

CONDUCTING ASSESSMENTS OF HEALTH CARE PROVIDERS WHO CARE FOR
WOMEN AND GIRLS AFFECTED BY FEMALE GENITAL MUTILATION/ CUTTING:
PSYCHOMETRIC VALIDATION AND QUALITATIVE EXPLORATION

by
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A dissertation submitted to Johns Hopkins University in conformity with the
requirements for the degree of Doctor of Philosophy

Baltimore, Maryland
September, 2020

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Abstract

Background: Female Genital Mutilation/C (FGM/C) is cultural practice associated with adverse obstetric, reproductive, and gynecologic health outcomes and no health benefits. Although more than 200 million women and girls have already been affected around the world, there are no validated instruments to assess health care providers for the care of women affected by FGM/C.

Methods: Using an explanatory sequential quantitative-qualitative design, we psychometrically assessed novel measures of health care provider attitudes and confidence for FGM/C care using exploratory factor analysis (EFA), explored the relationship between provider characteristics and health care provider attitudes and confidence using multivariable linear regression, and conducted in-depth qualitative interviews to explore expert opinion on the areas of knowledge, attitudes and practices that contribute to quality care for FGM/C.

Results: The EFA for attitudes resulted in subscales for *Negative Attitudes* and *Empathetic Attitudes* with Cronbach's alphas of 0.814 and 0.628 respectively. The EFA for confidence resulted in subscales for *Confidence in Clinical FGM/C Care* and *Confidence in Critical Communication Skills for FGM/C* with Cronbach's alphas of 0.857 and 0.694 respectively. The only statistically significant factor associated with either negative or empathetic attitudes was that women had significantly less *Negative Attitudes* compared to men. Factors associated with higher *Confidence for Clinical FGM/C Care* scores include awareness of health complications, having cared for a woman with FGM/C, being a woman or a person of color, and more than 5 years clinical practice. The only factor associated with increased *Confidence in Critical Communication Skills for FGM/C Care* was awareness of health complications of FGM/C. Participants in our qualitative study identified six areas of knowledge, six of practice, and seven of attitudes that contribute to quality care for FGM/C. We present prominent themes that

describe how the interaction between knowledge, attitudes and practices influence quality of care.

Conclusion: The study described herein combines rigorous psychometric analysis of measures of health care providers attitudes and confidence for FGM/C care in the US, and a qualitative exploration of expert opinion to advance our understanding of the knowledge, attitudes, and practices critical to the provision of quality care for FGM/C.

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Funding

Funding for this dissertation was provided by:

T32 Predoctoral Fellowship for the Study of Violence in the Family,
National Institute of Nursing Research T32-HDO64428, 2013-2015

TL1 Trainee Award, Predoctoral Clinical Research Training Program (PC RTP)
Johns Hopkins Institute for Clinical and Translational Research, 2015-2016

U.S. Department of Health and Human Services, Office on Women's Health (Grant
No. ASTWH160045)

Better Selves Fellowship – Writing Grant 2016

Professional Development Award, Travel Grant Johns Hopkins School of Nursing, 2016

Heilbrunn Nurse Scholar Award, Rockefeller University,
Heilbrunn Family Center for Research Nursing, 2018 – 2019

Office of Reproductive Health and Research,
World Health Organization, 2016 – 2019

Disclaimer: The content of this document is solely the responsibility of the author and does not necessarily represent the official views of the National Institutes of Health, World Health Organization, Heilbrunn Foundation, or other funding agencies.

Dedication

To my amazing, loving, supportive, insightful, kind, and generous partner Rico Marea. Thank you for every single day since January 30th 2016.

Acknowledgements

First, I would like to thank the study participants who participated in each portion of this study. I would like to especially thank the qualitative study participants who were generous with their time, gracious about scheduling, and deeply engaged in our discussions.

I would like to thank Crista Johnson-Agbakwu for welcoming me to your research team and the project with Arizona State University. It was wonderful to be part of such a warm and collaborative research team. I would like to thank Christina Pallitto and the Office of Reproductive Health and Research for their contributions to and support of the qualitative component of this project. And I would like to thank Nancy Glass, Nicole Warren, and Nancy Perrin for their support and perseverance through all the iterations of this project – I would not have gotten to the finish line without you. Any errors or emissions are completely mine.

Thank you to the Johns Hopkins University School of Nursing PhD faculty for a world-class educational experience. The examples you all have set as researchers are inspiring.

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Dissertation Organization

This dissertation is organized into five chapters. The first chapter provides background on the problem addressed by this research, an explanation of key concepts, a review of existing literature, and provides the conceptual frameworks used to guide analyses.

Chapter Two (Manuscript One) presents the findings of the psychometric validation of the Attitudes and Confidence Scales developed to assess health care providers caring for women and girls affected by FGM/C. These scales were validated using exploratory factor analysis. This chapter also presents hypothesis testing to assess the concurrent validity of the newly validated scales.

Chapter Three (Manuscript Two) presents the findings of the multivariate analysis that aimed to explore factors associated with health care provider awareness of complications, attitudes toward FGM/C, and confidence for the care for women affected by FGM/C.

Chapter Four (Manuscript Three) presents the findings of the qualitative study that aims to explore and expand upon the domains of knowledge, attitudes and practices for the care of women and girls affected by FGMC. This chapter provides details regarding the qualitative data collection, analysis, and creation of a domain framework.

Chapter Five provides a summary of results and discusses integration of results across the three manuscripts and within other existing literature. The chapter discusses implications of these results for future research, interventions, and policies.

CHAPTER 1: INTRODUCTION

Background and Rationale

200 million women and girls around the world that are affected by female genital mutilation/ cutting (FGM/C) require specialized health care to reduce disability and maximize quality of life.^{1,2} FGM/C includes procedures that intentionally alter or cause harm to female genital organs for non-medical reasons, and may result in a number of adverse obstetric, gynecologic, urologic, and psychosexual consequences.^{1,3} Despite the prevalence of FGM/C and its associated morbidities, there is not a validated instrument to assess health care provider knowledge for the care of affected populations.⁴⁻⁶ Many health care providers (nurses, nurse practitioners, social workers, and physicians) have limited or no training in the identification and care of women/ girls with FGMC.^{4,6-10} The lack of technical knowledge about the physical and psychosexual consequences of FGM/C, limited cultural competence and socio-cultural challenges, and lack of guidance of best practices for the care of women with FGMC result in health disparities compared to non-FGMC affected women, and adverse reproductive health outcomes.¹¹

Despite a fall in overall prevalence rates, the number of girls and women affected will rise, in coming decades because of persistently high fertility rates in FGM/C practicing countries.¹ Because of global migration trends, health care providers in countries where FGM/C is not normative are likely to care for affected women and girls.¹ FGMC may result in a number of adverse outcomes including but not limited to: obstetric (hemorrhage, cesarean section), gynecologic (recurrent infections), urologic (painful urination), and psychosexual (painful intercourse, anxiety, depression).¹²⁻¹⁸

Health care provider capacity around FGMC is often measured using a “Knowledge, Attitudes, and Practices” (KAP) framework; however, there is no standard or validated instrument to assess health care provider KAP. Existing studies design their own KAP instrument, often with very different items, limiting the comparability and generalizability of the findings. This lack of a reliable, valid tool limits efforts to adequately assess provider readiness to care for this population or gauge the success of efforts designed to improve their competencies. Centers for Disease Control (CDC) and WHO have on-going studies that include trainings for health care providers on caring for FGMC affected populations, but lack a validated instrument to assess trainings.

This overall goal of the study is to improve the assessment of health care providers caring for women and girls affected by FGM/C. We achieved this goal by addressing three specific aims. First, we constructed and assessed the reliability and validity of novel Attitudes and Confidence Scales to assess health care providers caring for women and girls affected by FGM/C in the US. These scales were validated using exploratory factor analysis. We further performed hypothesis testing to assess the concurrent validity of the newly validated scales. Second, using multivariate analysis, we explored factors associated with health care provider awareness of complications, attitudes toward FGM/C, and confidence for the care for women affected by FGM/C in the US context. Third, we conducted a qualitative study utilizing in depth interviews with clinical and research experts on FGM/C to explore and expand upon the domains of knowledge, attitudes and practices for the care of women and girls affected by FGM/C in a global context.

Improved assessment methods are critically needed so that health care organizations can evaluate health care providers caring for women and girls affected by FGM/C. This may include

baseline assessments, and evaluation of the effectiveness of health care provider training interventions.

Purpose

The overall purpose of this dissertation was to construct and psychometrically assess measures of health care provider attitudes and confidence for the care of women and girls affected by FGM/C, and to advance our understanding of the knowledge, attitudes, and practices of health care providers that contribute to quality care for women and girls affected by FGM/C. This explanatory sequential quantitative-qualitative study will 1) construct and validate novel measures of health care provider attitudes and confidence for FGM/C care, 2) examine the relationship between health care provider attitudes and confidence for FGM/C care and other health care provider experiences and characteristics, and 3) explore knowledge, attitudes and practices important for quality care through qualitative interviews with clinical and research experts for FGM/C care. The quantitative study occurred first in order to rapidly develop and validate a measure for use in an ongoing research study at Arizona State University that aimed to conduct baseline assessments and training of US health care providers for FGM/C care. The qualitative study was conducted in collaboration with the World Health Organization Office of Reproductive Health and Research and aimed to create a framework for the development of a comprehensive knowledge, attitudes, and practices measure for use global settings.

This study can improve the quality of assessment through the development of standardized measures to assess health care provider attitudes and confidence for the care of this vulnerable population (minority women and affected by FGM/C) in the US context. This data can inform future trainings that aim to transform attitudes and increase US health care provider confidence for the provision of care to this marginalized population. By exploring the expert

opinion of a global sample of clinical and research experts in FGM/C, we can further advance our understanding of what comprises quality care, and design comprehensive training interventions that promote well-being for women and girls living with FGM/C.

Specific Aims

The following specific aims were proposed:

Specific Aim 1 (Quantitative) Assess the psychometric properties and factor structure of novel measures of health care provider attitudes and confidence for the care of women and girls affected by FGM/C.

Specific Aim 1.1 Utilize exploratory factor analysis to assess the factor structure and psychometric properties of the newly developed attitudes scale.

Specific Aim 1.2 Assess concurrent validity of the attitudes scale by testing the following hypotheses:

Hypothesis 1.2.1: Health care providers who have cared for women or girls affected by FGMC, received training on FGM/C, who identify as nurses/ mental health/ social workers, providers specializing in women's health, women, and people of color will have more empathetic and less negative attitudes than health care providers who have not had these experiences or who do not share these characteristics.

Specific Aim 1.3 Utilize exploratory factor analysis to test the factor structure and psychometric properties of the newly developed confidence scale.

Specific Aim 1.4 Assess the concurrent validity by testing the following hypotheses:

Hypothesis 1.4.1: Health care providers who have cared for women or girls affected by FGM/C, received training on FGM/C, and who specialize in women's health will have higher scores on the confidence subscales compared to health care providers who have never cared for a woman or girl affected by FGMC.

Specific Aim #2 (Quantitative) Explore the relationship between health care provider demographic characteristics, previous clinical experience related to FGM/C, awareness of health complications associated with FGM/C, attitudes towards FGM/C and those who practice FGM/C, and confidence for the care of women and girls affected by FGM/C using multivariable regression.

Exploratory Aim 2.1 Explore the relationship between health care provider awareness of complications of FGM/C and demographic factors, previous clinical experience related to FGM/C.

Exploratory Aim 2.2 Explore the relationship between health care provider *Negative Attitudes Toward FGM/C and those who practice* and demographic factors, previous clinical experience related to FGM/C, and awareness of health complications of FGM/C.

Exploratory Aim 2.3 Explore the relationship between health care provider *Empathetic Attitudes Toward FGM/C and those who practice* and demographic factors, previous clinical experience related to FGM/C, and awareness of health complications of FGM/C.

Exploratory Aim 2.1.4 Explore the relationship between health care provider *Confidence for Clinical FGM/C Care* and demographic factors, previous clinical experience related to FGM/C, and awareness of health complications of FGM/C.

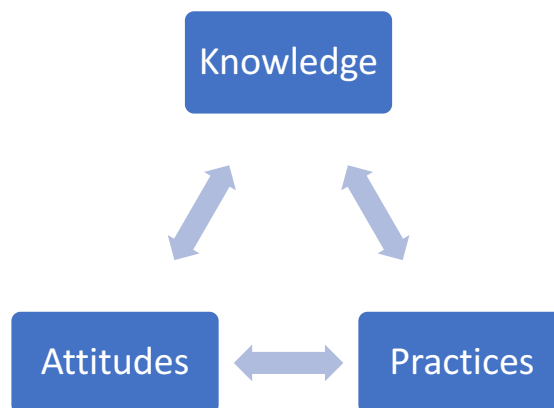
Exploratory Aim 2.5 Explore the relationship between health care provider *Confidence in Critical Communication Skills for FGM/C* and demographic factors, previous clinical experience related to FGM/C, and awareness of health complications of FGM/C.

Specific Aim #3 (Qualitative) Explore the knowledge, attitudes, and practices that global clinical and research experts in FGM/C consider important to ensure high quality, safe, and effective care for FGMC-affected women and girls using qualitative in-depth individual interviews.

Conceptual Framework

This study was guided by the *Knowledge, Attitudes, and Practices (KAP)* framework which is often used to assess health behaviors, including the behaviors of health care providers during the course of care provision. The KAP framework seeks to address the relationship between knowledge and behavior, theorizing that attitudes may affect the relationship. The KAP framework theorizes that an individual learns about a topic (knowledge), develops some affective response (attitude), and engages in a behavior (practice) – often these factors influence one another in multidirectional ways.¹⁹ See Figure #1.

Figure 1 Knowledge, Attitudes and Practices Framework



In order to create an effective measure of health care provider knowledge, attitudes and practices for FGM/C, it is imperative that researchers define what constitutes critical knowledge for FGM/C, attitudes that affect FGM/C care, and practices that constitute quality care for FGM/C. However, at the outset of this dissertation research in 2017, there was no current published comprehensive guide that enumerated what constituted quality care for women and girls living with FGM/C. During the course of this research, the WHO published a *Care of Women and Girls Living with Female Genital Mutilation: A Clinical Handbook* which provides a comprehensive overview of the knowledge and practices that constitute quality care. The Clinical Handbook does not provide a comprehensive framework of how attitudes contribute to the patient's experience of quality care

As we sought to develop a measure of health care provider attitudes toward FGM/C, and an interview guide to explore the concept of attitudes in the context of FGM/C care, we utilized the conceptualization of attitudes theory to inform our work.^{20,21} This theory proposes that attitudes are constructed through the reciprocal interplay of *affect*, *belief*, and *behavior* and can be the tendency that is expressed as we assign particular entity or concept with favor or disfavor.²² *Affect* is the feeling that an individual may experience in relation to the concept under investigation. The way a provider feels about FGM will affect how they feel about the performance of FGM, the women who undergo/ have undergone FGM, and the communities that practice FGM. *Beliefs* are thoughts about the relationship between a concept and a given attribute; for example, an individual may believe that FGM/C is a barbaric practice, or alternately that it is a culturally beneficial practice. Individuals process their experiences, observations, knowledge, and culture regarding a concept and develop a belief about the value, causes, and outcomes of the object/ experience. The beliefs of health care providers related to FGM will be

explored in qualitative interviews in order to better understand the range of beliefs providers may hold, and how those beliefs affect the care that they provide. *Behaviors* include the actions taken by the individual and may be influenced by selective attention to certain affective responses or beliefs, while disregarding others. In the case of FGM, health care provider behavior may be related to unconscious or learned patterns of behavior based on past experience or may depend on how much exposure a health care provider has had to FGM and under what circumstances. The relationship between behaviors and beliefs/ affect may be inconsistent and depend factors related to the individual health care provider, their clinical training, and their clinical practice.

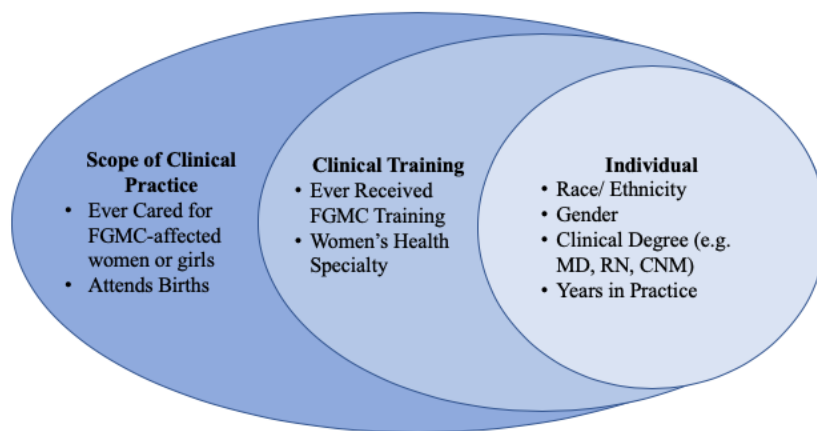
In order to create the items to measure health care provider attitudes, we next had to determine attitudes toward *which* object were important to the provision of quality care for FGM/C. Based on our exploration of qualitative literature of the experiences of women with FGM/C receiving care, and health care providers experiences providing care to those affected by FGM/C, we determined that there were three types of attitudes we sought to measure 1) attitudes toward FGM/C as a practice, 2) attitudes to women who have experienced FGM/C and 3) attitudes towards families and communities that practice FGM/C. Attitudes toward the practice of FGM/C may include strongly negative attitudes such horror or disgust.^{23,24} Because FGM/C is not a normative practice in the USA, we conceived of the other end of the attitude spectrum as empathetic toward FGM/C rather than supportive or positive. We therefore also sought to include items to assess attitudes which may demonstrate that the provider understands that this practice may be meaningful and desired by the person who has undergone the FGM/C, their family or community.²⁵

We used a modified ecological framework as we conduct the psychometric analysis and validity testing of the new attitudes and confidence scales. An ecological framework posits that

any behavior must be understood in the context of individual, institutional, community, and societal factors. For this analysis, we focused on the individual, clinical training and clinical practice characteristics. Individual factors that may affect health care provider knowledge, attitudes, and practices for the care of those living with FGMC may include individual characteristics like their race or ethnicity, gender, and clinical degree. Factors related to clinical training include a clinical specialties related to women’s health, or having received training for FGM/C. Clinical practice characteristics may include if they care for women with FGM/C, or attend births.

See figure #2.

Figure 2 Factors Influencing the Health Care Provider Care for Those Living with FGM/C



This study was further informed by the World Health Organization (WHO) framework elaborating the critical attributes that define *quality care*; it is effective, efficient, accessible, patient-centered, equitable, and safe.²⁶ The operational definitions of each component of quality of care is provided in Table #1.

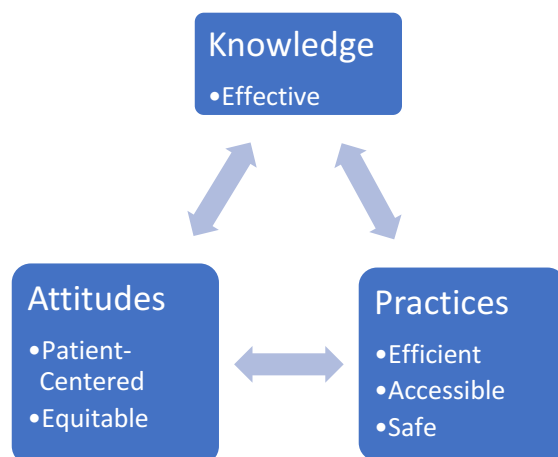
Table 1 Dimensions of Quality of Care

| | |
|-------------------|---|
| <i>Effective</i> | Health care that is based on scientific knowledge and evidence-based guidelines |
| <i>Efficient</i> | Health care delivered in a manner that maximizes resource use and avoids waste |
| <i>Accessible</i> | Health care that is timely, geographically reasonable, and provided in a setting where skills and resources are appropriate to medical need |

| | |
|-------------------------|---|
| <i>Safe</i> | Health care that minimizes risks and harm to service users, including avoiding preventable injuries and reducing medical errors |
| <i>Patient-Centered</i> | Health care that takes into account the preferences and aspirations of individual service users and the cultures of their communities |
| <i>Equitable</i> | Health care that does not vary in quality because of personal characteristics such as gender, race, ethnicity, geographical location, or socioeconomic status |

As we sought to conceptualize and study the knowledge, attitudes, and practices of health care providers caring for women and girls affected by FGM/C, we further explored how each of these aspects of quality of care were related to knowledge, attitudes and practices. See Figure #3.

Figure 3 Knowledge, Attitudes and Practices for Quality Care



We propose that *knowledge for FGM/C care* includes the cognitive awareness of the scientific and evidence-base content that contributes to care that is effective for improving the desired health outcomes of the patient. *Practices for FGM/C care* are those behaviors by the health care provider that demonstrate delivery of care that is efficient, accessible, and safe. *Attitudes for FGM/C care* would be those affective responses of the health care provider that affect the patient-centeredness or equity of either how care is delivered (practices) and/ or what care is offered (knowledge).

The KAP framework has been used frequently to assess health care providers for the care of women and girls affected by FGM/C; however, we were not able to identify any validated

measures for FGM/C.⁴ Existing studies assessing health care providers' knowledge, attitudes, and practices do not define these terms nor provide operational definitions of what constitutes these domains for FGM/C care. Existing studies typically report their results as purely descriptive, without exploring the relationships between knowledge, attitudes and practices or considering health care provider characteristics, such as demographics or past experiences with FGM/C, as confounders to these relationships.^{4,27}

FGM/C is a practice affecting approximately 200 million women and girls around the world, yet there are no validated instruments to assess health care providers caring for women affected by FGM/C, and there is a lack of formative research on the knowledge, attitudes and practices of health care providers that constitute quality care for those affected by FGM/C. Investigators tend to develop new instruments without conducting validation procedures, resulting in measures that have notable gaps in terms of their conceptualization and content despite very similar aims.

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CHAPTER 2: MANUSCRIPT ONE

Assessing the Reliability and Validity of Attitudes and Confidence Scales for the Care of Women and Girls Affected by Female Genital Mutilation/Cutting

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Proposed Journal: BMC Public Health

Date of Submission: *pending*

Abstract

Background: Approximately 545,000 women and girls living in the USA have either undergone Female Genital Mutilation/ Cutting (FGM/C) or have mothers from one of the FGM/C-practicing countries throughout Africa, the Middle East and South Asia. Health care provider attitudes towards the practice of FGM/C and confidence in their ability to address health needs related to FGM/C may affect the perceived quality of care by patients. However, there is currently no validated measure of provider attitude and confidence in the provision of care for patients with FGM/C. The lack of a validated measure limits our ability to assess health care provider attitudes and confidence, including the impact of trainings that aim to transform health care provider attitudes and confidence.

Methods: We used a 3-stage instrument development process: 1) a systematic review of the FGM/C literature; 2) the development of attitude and confidence assessment items; and 3) an expert review and pre-testing of the developed measures. Next, we validated the instruments by piloting it among a diverse sample of health care providers in Arizona and Maryland. Finally, each subscale underwent psychometric validation using exploratory factor analysis to confirm factor structures.

Results: We tested 13 attitudes and 11 confidence measurement items in this psychometric validation study. The exploratory factor analysis (EFA) revealed a two-factor solution for attitudes, including a scale for *Negative Attitudes* and *Empathetic Attitudes* toward FGM/C and those who practice FGM/C with Cronbach's alpha coefficients of 0.814 and 0.628 respectively. The EFA for the confidence scales also revealed a two-factor solution including *Confidence in Clinical FGM/C Care* and *Confidence in Critical Communication Skills for FGM/C Care* with Cronbach's alpha coefficients of 0.857 and 0.694 respectively.

Discussion: FGM/C is a significant public health issue that health care providers are not adequately trained to address. Our study combines comprehensive review of the literature, expert opinion, and rigorous psychometric analysis to create a reliable and valid instrument to assess health care provider attitudes and confidence in the care of women and girls who have experienced FGM/C.

Trial Registration: Clinical Trials.Gov ID # NCT03249649, Study ID# 5252. Public website: <https://clinicaltrials.gov/ct2/show/NCT03249649>

Background

Female Genital Mutilation/ Cutting (FGM/C), a cultural practice with no health benefits, involves the cutting and/or removal of parts of the external female genitalia. According to UNICEF and the World Health Organization (WHO), FGM/C is practiced in certain communities across approximately 31 countries in Africa, the Middle East and South Asia, with its prevalence varying dramatically between and within countries.^{1,2} Motivations for the practice are diverse and may relate to beliefs about cleanliness, sexual norms, rites of passage, marriageability and/or group membership.^{27–29} The WHO has enumerated 33 possible health complications associated with FGM/C, which range from immediate post-FGM/C, physiological (obstetric, gynecologic, sexual) to psychological impacts.² The WHO has classified FGM/C into four major types depending on the extent of tissue cut or removed and whether the vaginal opening is also narrowed. While all FGM/C types are associated with health complications, not everyone who has undergone FGM/C will experience them. Women with more extensive or severe cutting tend to have worse morbidity.¹⁴ In 2016 and 2018 respectively, the WHO published *Guidelines on the Management of Health Complications from FGM* and *Care of Women and Girls Living with FGM: A Clinical Handbook* which provide comprehensive guidance on the clinical care for those living with FGM.^{2,30}

Recent estimates from 2012 indicate that 545,000 women and girls living in the US may have either undergone FGM/C or were born to mothers from a country where FGM/C is practiced—an increase of 224% since 1990.³¹ As women and girls from families that practice FGM/C are born in or migrate to settings where the practice is non-normative, they may interact with healthcare providers who are unaware of FGM/C and who do not have the knowledge or confidence to provide evidence-based care. Even if a health care provider is confident in their

ability to provide quality care, they may hold attitudes that create barriers in the patient-provider relationship.²⁴ When health care providers encounter a patient with FGM/C, they may experience a strong affective response from anger toward the practice of FGM/C to empathy for the women who experienced it.²³ Challenges with cross-cultural communication can be further compromised for patients with low-English proficiency if the provider is not confident in their ability to conduct a visit via interpreter.^{32–34} Disagreements (such as whether to perform cesarean birth) and difficulties in communication can result in a lack of confidence in and distrust of providers by the patients.^{35,36} Some women with FGM/C prioritize minimizing interventions; this may be perceived by providers, who may not have actively listened to the patient's perspective or priorities, as antagonist or ill-informed.^{37,38} Health care providers may experience frustration when patients express distrust or refuse recommended care.³³ Women and girls who have experienced FGM/C deserve quality care, yet evidence suggests that they often do not receive it.^{37,39–42}

According to the WHO, *quality care* is effective, efficient, accessible, patient-centered, equitable, and safe.²⁵ Current studies of health care providers and their patients affected by FGM/C show that FGM/C-related care is often ineffective and inequitable due to a lack of provider knowledge, training and confidence in their ability to provide appropriate care for FGM/C-related complaints.^{23,32,43} For example, a recent meta-synthesis of the birth experiences of FGM/C-affected women in the context of migration revealed anxiety and fear related to their pervasive perception that health care providers do not know how to care for them.³⁷ Women with FGM/C often distrust health care providers who they feel lack the knowledge and confidence to provide high quality care for FMG/C related complaints.^{37,43–48} This distrust can result in women

with FGM/C being less likely to seek or access reproductive health care⁴⁹ or to decline recommended care.³³

Effective care for women affected by FGM/C should be based on scientific knowledge and evidence-based guidelines.²⁵ For example, an important intervention for women with Type 3 FGM/C is defibulation, which is the surgical release of the scar covering the vaginal opening. Because of the lack of training in this technique, many obstetric providers in the USA lack the knowledge and confidence to adequately counsel women about this procedure or to perform it.⁵⁰ Providers who are knowledgeable about FGM/C have likely learned while caring for patients with FGM/C, rather than received training in advance.^{50,51} Experience caring for patients with FGM/C may impact the options offered to patients, including procedures like reinfibulation (the partial or complete re-closing of the infibulation scar after it has been defibulated), which some consider a form of FGM/C while others maintain adult women should be able to determine whether and to what extent the scar is reclosed.⁵² Clinicians with women's health specialties and those with previous experience caring for those affected by FGM/C were more likely to report they would perform reinfibulation if asked by their patient as compared with providers without that expertise or those experiences.⁵⁰ Though health care providers in the US may be unlikely to support FGM/C, they can demonstrate empathy for women who have undergone FGM/C through communication skills, such as active listening and non-judgmental responses, or through practices that demonstrate effective care, such as performing reinfibulation or discussing harm reduction strategies. Health care providers must be confident in their ability to provide quality care and to manage complex cultural and ethical discussions in order to promote the desired health outcomes of patients affected by FGM/C.

Existing Measures of Attitudes and Confidence for FGM/C-Related Care

Health care provider attitudes and confidence impact the quality of care received by patients affected by FGM/C, yet there are few existing instruments to measure these constructs. Existing measures are characterized by the lack of psychometric assessments to determine their reliability or validity. Authors use no^{53,54} or limited validation procedures including expert review^{55–57} and pre-testing.^{50,55,56,58,59} These measures lack conceptual definitions of attitudes and confidence and do not explain the rationale for item selection.

To inform a new measure, we reviewed existing measures of attitudes created for use in high resource countries where FGM/C is not normative to inform our own measure. We selected a working definition of *attitudes* to inform our review and instrument development. Attitudes are the expression of an individual's tendency of favor or disfavor expressed toward a particular entity.²² Existing measures tend to include items that focus on ethical issues related to FGM/C (e.g., whether adult women have the right to elect FGM/C or whether the respondent considers FGM/C a violation of human rights and/or a form of violence against women), which may provide insight into how providers respond to patients with FGM/C and what types of treatments are offered.^{7,50,58,60} The items assessing attitudes towards ethical issues tended to have agree/disagree Likert scale type responses. Endorsement of items related to the rights of women and families to choose FGM/C for themselves or their daughters may give some indication of a provider's intention to engage in these practices or support someone who elects to do so. In addition, they may indicate health care provider empathy, or willingness to see the patients' perspective in terms of what FGM/C means to her and her family. Other items included in existing attitudes measures are more accurately described as knowledge (e.g., whether FGM/C is a religious or cultural practice), or contextual questions (e.g., whether FGM/C is legal in their

jurisdiction, mandatory child protective services reporting requirements, awareness of intentions to cut a girl child in the community or by traveling abroad [*vacation-cutting*]).⁶⁰ Additional attitudes items asked respondents to state how they *would* respond to a patient affected by FGM/C.¹⁰ However, these types of items should be considered outcome variables that are influenced by attitudes, rather than attitude measuring items. For example, a health care provider might be more likely to report the patient to the authorities if they view FGM/C as a crime.

Existing measures of attitudes tend to focus on attitudes toward FGM/C as a practice, rather than attitudes towards the women, girls, and communities that are affected by or support FGM/C. Negative attitudes toward those affected by FGM/C are important to measure because a health care provider's negative attitude toward a person on the basis of irrelevant characteristics such as race or language proficiency (also known as implicit bias) has been shown to negatively affect clinical care including diagnosis, treatment decisions, health outcomes, non-verbal behaviors, and patient-provider interactions.^{61,62} Most women and girls affected by FGM/C in the USA are of African, Asian or Middle Eastern descent – groups where 50-75% of individuals surveyed report experiencing bias or discrimination in the health care setting.^{62,63} They also report reduced experiences of bias when they have a health care provider who shares their racial or ethnic identity.^{62,64} Women and girls who have experienced FGM/C embody multiple identities that, within the USA, can render them vulnerable to bias and discrimination including immigration/ refugee status, low-English proficiency, and being a person of color.^{24,61,65}

Few measures assess health care provider confidence for the care of women and girls affected by FGM/C. During our review, we identified only two studies since 2007 that assessed health care provider confidence. Both measures have notable limitations, including the lack of a conceptual definition of confidence and no operational definition to explain the rationale behind

item development.^{54,57} Self-reported confidence in a particular skill is also termed *self-efficacy* and can explain, in part, the actual performance of that skill.⁶⁶ Self-efficacy is the perceived capability to perform a behavior and is a robust predictor of whether someone will engage in a target behavior.⁶⁷ Their main limitation of one study is that the items encompassed multiple concepts, thereby limiting score interpretability as it is unclear as to which aspect of the item respondents considered in their responses.⁵⁴ Despite limitations, many concepts were important to consider for our measure including confidence for discussing defibulation, to identify and manage FGM/C, documentation, and counseling.^{54,57}

Existing measures of health care provider attitudes and confidence provide some insights into challenges of providing FGM/C related care, and what types of attitudes health care providers hold. The current literature on health care provider attitudes and confidence would be strengthened by measures that utilize clear conceptual definitions of attitudes and confidence, that hypothesize relationships between attitudes and confidence, have undergone psychometric testing, and that enable researchers to explore the relationships between attitudes, confidence, and other provider characteristics. In this study, we describe the development and psychometric assessment of novel measures of attitudes and confidence of health care providers caring for women and girls affected by FGM/C. The *Health Care Providers Attitudes Toward FGM/C and Those Who Practice FGM/C* scale captures providers' empathetic and negative attitudes. The *Health Care Provider Confidence for FGM/C* scale assesses health care providers confidence in providing care for and communicating with women and girls affected by FGM/C. Our instruments can be used to understand provider attitudes and confidence about FGM/C before and after trainings to generate a baseline understanding of these competencies and allowing for

comparisons between providers in different settings. This information can also be used to evaluate the impact of training on these important factors related to quality of care.

Methods

Instrument Construction

We drafted the items for the attitudes and confidence scales following an exploration of the qualitative literature addressing patient experiences receiving care and health provider experiences providing care related to FGM/C. Authors CM (Nurse-Midwife) and CJA (OB/GYN) discussed the attitudes- and confidence-related domains that emerged from the literature review and considered their own experiences providing care for patients affected by FGM/C. We sought to develop attitude items that may affect quality of care for patients who have experienced FGM/C including negative and empathetic attitudes toward FGM/C, and those affected by the practice. Negative attitudes include attitudes held by the health care provider that might lead them to express, or a patient to experience, discrimination or bias related to their FGM/C status. Empathetic attitudes include attitudes that might lead the health care provider to prioritize a patient-centered approach to FGM/C-related care. We also included items assessing possible support for medicalization or a harm reduction approach to FGM/C in our empathetic attitudes measure.

We determined that there were broadly two areas of confidence that directly influenced the effectiveness, and equitable patient-centered delivery of care to patients affected by FGM/C: confidence for the provision of clinical care, and confidence in the ability to communicate effectively. Ideally, we would directly observe provider care; however, given the ethical and practical challenges, self-reported confidence is used as a proxy measure. We developed the confidence measure to assess confidence for clinical care and communication and aligned them

with key components of a provider-patient encounter. Items related to clinical care included gathering subjective and objective data, making an assessment, and developing a patient-centered treatment plan. Specifically, for patients affected by FGM/C, this would include identifying FGM/C, determining its type, documenting its presence, and discussing potential complications and their management. Critical communication skills for care of patients affected by FGM/C include the ability to effectively conduct visits via an interpreter, provide evidence-based treatment options, maintain rapport with a patient who is declining recommended care, engage in non-judgmental listening and shared-decision-making.

Expert Review and Pre-Testing

Clinical FGM/C experts including an obstetrician/ gynecologist, a nurse-midwife, and a pelvic floor physical therapist reviewed the thirteen attitudes and eleven confidence items for content validity. We circulated a shared document adding comments and edits that were integrated by CM. Comments included grammatical adjustment, clarifying wording to avoid jargon, and simplifying sentence structure. One attitudes item was dropped because it contained multiple clauses and was thus responses were not interpretable. No other items were added or dropped. Next, a nurse-midwife and medical resident who are not FGM/C experts reviewed the instrument for clarity and understandability while seated with CM. CM inquired what they thought each question was intending to ask to ensure that their interpretation was consistent with our intention. No issues arose during this review, and no further revisions were suggested. The survey was then pre-tested among a convenience sample of 3 medical students, 2 medical residents, and 2 nurse-midwives with no previous FGM/C-related training in current clinical

practice in the Phoenix and Baltimore-DC areas. The full survey took approximately 7-10 minutes to complete. No further edits were suggested by the pilot testers.

Study Setting

We conducted an online cross-sectional survey of health care providers at the time of registration in a workshop titled “Optimizing Care for Women and Girls Affected by FGM/C” in the greater Phoenix and Tucson, Arizona and Baltimore, Maryland areas. This workshop and study were conducted as part of a multi-phase study that aimed to identify and address gaps in care for women and girls affected by Female Genital Mutilation/Cutting (FGM/C).

Recruitment and Study Population

Health care providers were invited to register for the workshop and complete the survey via emails that were distributed to list-servs at 14 health care institutions in Phoenix and Tucson, Arizona metropolitan areas. Arizona List-servs included between 80-400 contacts. The survey was broadly distributed within the Johns Hopkins Health System and Johns Hopkins University Schools of Medicine, Nursing and Public Health as well as to professional organizations in the greater Baltimore, Maryland and Washington D.C. area. The primary list-serv contacts included nursing and residency training program directors, medical directors, nursing and medical faculty, and hospital department chairs, and points of contact for local chapters of professional organizations such as AWHONN, ACNM, and ACOG.

The study population included health care providers who registered for the workshop and completed the online survey at the time of registration. A broad sample of health care providers registered for the workshop and completed the baseline survey, including physicians, residents,

nurses, nurse-practitioners, nurse-midwives, physicians assistants, mental health workers, social workers, and students in the health professions.

Measures

The survey included demographic and scope of clinical practice questions, as well as items to assess previous FGM/C related clinical experiences and familiarity with FGM/C terminology and procedures. The *Health Care Providers Attitudes Toward FGM/C and Those Who Practice FGM/C* scale included twelve items total, with five that assessed negative and seven items that assessed empathetic attitudes toward FGM/C, communities and families that support FGM/C, and women who have experienced FGM/C. *See table #2 for all Attitude items.* The *Health Care Providence Confidence for FGM/C Care* measure included five items that assessed key aspects of clinical care for women and girls who have undergone FGM/C including: FGM/C case and type identification, documentation of FGM/C care using appropriate codes, interpreter use, and provision of counseling regarding health complications of FGM/C. The remaining three items assessed confidence in critical communication skills for FGM/C care, including those related to listening, counseling, and interpreter use. *See Table #3 for all confidence items.* For both the *Attitudes* and *Confidence* scales, participants were asked to read each statement and then mark their level of agreement with the given statements on a four-point Likert-scale from “4=Strongly Agree” to “1=Strongly Disagree.”

Table 2 Health Care Providers Attitudes - Items

| | <i>Negative Attitudes Toward FGM/C and Those Who Practice FGM/C</i> |
|---|--|
| 1 | FGM/C is a violation of human rights |
| 2 | Communities that practice FGM/C are oppressive towards women. |
| 3 | Health Care Providers who perform any form of FGM/C, including symbolic nicking, should be charged with a crime. |
| 4 | Parents who have their daughter circumcised are abusing them. |

| | |
|----|--|
| 5 | Women who have undergone FGM/C are victims of an oppressive cultural practice. |
| | <i>Empathetic Attitudes Toward FGM/C and Those Who Practice FGM/C</i> |
| 6 | Symbolic nicking or cutting of the female genitalia is an effective way to reduce the harm of FGM/C compared to more extensive procedures. |
| 7 | Communities that practice FGM/C are honoring an important cultural tradition. |
| 8 | Adult women have the right to undergo FGM/C. |
| 9 | Parents who have their daughter circumcised are protecting her future marriage prospects. |
| 10 | Women who have undergone FGM/C are empowered agents. |
| 11 | Parents have the right to have their daughters circumcised (undergo FGM/C). |
| 12 | Health care providers should perform reinfibulation (re-closing of the vulvar scar following childbirth) if the woman requests it. |

Table 3 Health Care Provider Confidence - Items

| | |
|---|---|
| 1 | On inspection of the female genitalia, I can identify a woman with FGM/C |
| 2 | On identification of a woman with FGM/C, I can assign the appropriate WHO Type classification |
| 3 | On identification of a woman with FGM/C, I can appropriately code a visit to document the presence and type of FGM/C using ICD-10 and CPT codes |
| 4 | Conduct an effective reproductive/sexual health history via an interpreter |
| 5 | Respond to the health concerns of women with FGM/C by engaging in non-judgmental listening |
| 6 | Counsel women on the possible complications she may experience related to FGM/C |
| 7 | Discuss defibulation with pregnant women who have undergone Type 3 FGM/C in a culturally sensitive manner |
| 8 | Create a positive therapeutic relationship with a patient who refuses a recommended procedure |

For both the Attitudes and Confidence scales, participants were asked to rate their agreement with the given statements on a four-point Likert-scale from “4=Strongly Agree” to “1=Strongly Disagree.”

Statistical Methods

We used SPSS version 26. We examined construct validity for each scale using exploratory factor analysis (EFA) with principal axis factoring and oblimin rotation. Factor loadings above 0.40 were considered as loading on a given factor, and those below were considered for revision or elimination from the scale. We reviewed the items loading on each factor to ensure they comprised interpretable constructs and distinct subscales. We used Cronbach’s alpha to assess the internal consistency reliability for each subscale.

We assessed validity by comparing known groups using independent t-tests; p-values <0.05 were considered significant. For the attitude scales, we tested the a priori hypotheses that health care providers 1) with previous FGM/C training; 2) who have ever cared for a patient affected by FGM/C; 3) who identify as nurses, social workers, or mental health specialists; 4) whose clinical practice focuses on women's health; 4) who are of color; and 6) who are women will have less negative attitudes and more empathetic attitudes toward FGM/C and those who have experienced FGM/C. For the confidence scale, we tested the a priori hypotheses that those 1) who have had previous FGM/C training; 2) who have cared for a patient affected by FGM/C; and 3) whose clinical practice focuses on women's health will have greater confidence for the care of those affected by FGM/C.

Results

Enrollment and Participant Characteristics

A total of 796 individuals attended training events in Arizona and 101 in Maryland for 897 possible survey participants. A total of 369 participants initiated the online survey, of whom 14 did not provide any responses following the informed consent screen. The remaining 354 participants completed the online survey for a response rate of 39.5%. Exploratory factor analysis requires that all participants have completed all items to be included in the analysis. For the Attitudes scale, 291 (82.2%) participants completed all items and were included in the EFA. For the Confidence scale, we limited analysis to health care providers who are licensed independent providers, defined as physician or an individual licensed and authorized to write medical orders to provide care for a patient, and thus able to provide the outpatient medical care that *Confidence* scale items address (n=169, 47.7% of the total sample) including physicians and medical residents (MD), midwives (CNM), and nurse practitioners (NP) of whom n=143

(84.6%) completed all Confidence items. There were no significant differences in any participant characteristics between completers and non-completers. Participants for the total sample were predominantly female (81.4%), white (67.5%), and had a clinical specialty outside of women's health (65.0%). Demographics were similar for the attitudes and confidence sub-groups; however, among the sample for the confidence scale more participants were white (77.6%) and had a women's health focus in their clinical practice (52.4%). See table #4 for detailed participant characteristics

Table 4 Participant Characteristics

| | <i>All Health Care Providers Attitudes EFA** (n=291)</i> | <i>Licensed Independent Providers Only Confidence EFA** (N= 143)</i> |
|---|--|--|
| | N (%) | N (%) |
| Gender | | |
| - Female | 240 (82.5) | 108 (75.5) |
| - Male | 37 (12.7) | 28 (19.6) |
| - Missing/ Declined/ Other | 14 (4.8) | 7 (4.9) |
| Race/ Ethnicity | | |
| - Person of Color | 97 (33.3) | 33 (23.1) |
| - Black/ African American | 30 (10.3) | 8 (5.6) |
| - Asian | 31 (10.7) | 15 (10.5) |
| - Latino/ Hispanic; Native American; Other (non-white)* | 35 (12.0) | 10 (6.8) |
| - White | 194 (66.7) | 109 (76.2) |
| Clinical Practice | | |
| - Licensed Independent Provider | 138 (47.4) | |
| - Resident | 70 (24.1) | 72 (50.3) |
| - Physician | 38 (13.1) | 37 (25.9) |
| - CNM | 22 (7.9) | 25 (17.5) |
| - NP | 8 (3.4) | 9 (6.3) |
| - Other Health Care Provider | 153 (52.6) | -- |
| - RN | 38 (13.1) | -- |
| - Social Work | 9 (3.1) | -- |
| - Mental Health | 8 (2.7) | -- |
| - Student | 72 (24.7) | -- |
| - Other/ Missing | 11 (6.2) | -- |
| Women's Health Specialty | | |
| - Yes | 86 (29.6) | 74 (51.7) |
| - No | 189 (64.9) | 62 (43.4) |
| - Missing | 16 (5.5) | 7 (4.9) |
| Scope of Practice includes BIRTH (Ob/Gyn, Midwife) | | |
| - Yes | 67 (23.0) | 73 (51.0) |
| - No | 208 (71.5) | 63 (44.1) |
| - Missing | 16 (5.5) | 7 (4.9) |

*Due to small sample size for these demographic groups, they were combined to protect participant privacy.

**Demographics for participants who completed all items for the respective scale.

In terms of clinical experiences related to FGM/C, among the full sample of health care providers fewer than half have ever cared for a woman or girl who had experienced FGM/C (44.0%), though among licensed independent health care providers two-thirds had cared for someone who had experienced FGM/C (69.4%). Most participants had not received any formal training regarding FGM/C. Among licensed independent health care providers, most were aware of defibulation (68.7%) and the WHO FGM/C Type system (59.59%). Only about one-tenth of obstetric health care providers (Ob/Gyns and Midwives) had been trained to perform defibulation (11.9%). See table #5 for additional details about the FGM/C related clinical experiences of the participants.

Table 5 FGM/C Clinical Experiences

| | Attitudes EFA <i>All Health Care Providers</i> (n=291) | Confidence EFA <i>Licensed Independent Providers Only</i> (N= 143) |
|--|--|--|
| <i>Ever Cared for Patient with FGM/C</i> | | |
| - Yes | 128 (44.0) | 99 (69.2) |
| - No | 163 (56.0) | 44 (30.8) |
| <i>Previous FGM/C Training</i> | | |
| - Yes | 101 (34.7) | 64 (44.8) |
| - No | 190 (65.3) | 79 (55.2) |
| <i>Aware of Defibulation?</i> | | |
| - Yes | 135 (46.4) | 98 (68.5) |
| - No | 156 (53.6) | 45 (31.5) |
| <i>OB/ GYN and Midwives*</i> | (n=67) | |
| <i>Trained in Defibulation</i> | | |
| - Yes | 8 (11.9) | |
| - No | 46 (68.7) | |
| - Missing | 13 (19.4) | |

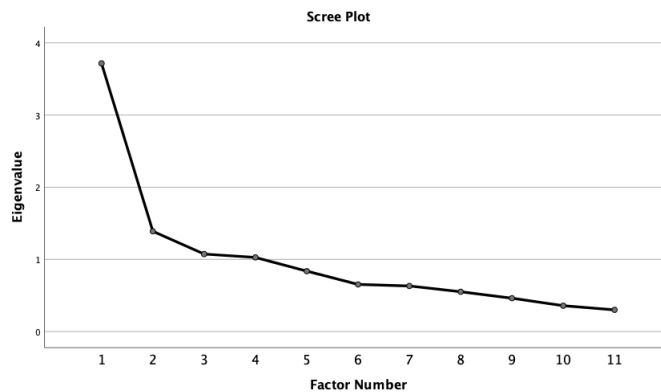
*Participants for whom defibulation is within their scope of practice

Results – Psychometric Testing for Attitudes

We began the exploratory factor analysis by reviewing the cases for completeness which demonstrated 3-9.9% missing responses per item. No items were eliminated due to missingness. We reviewed the variance of each item and eliminated one item because it had minimal variance with greater than 93% responding either disagree/ strongly disagree (*Parents have the right to have their daughters circumcised (undergo FGM/C)*). The lack of variance in this item may be

because FGM/C is commonly considered a violation of human rights in the USA. The eigenvalues (first 5 were 3.72, 1.39, 1.07, 1.03, 0.84) suggested that the 11 items formed two factors, which we confirmed using a scree plot visualization to identify the two factors above the break in the plot. See figure #4 for the Scree Plot.

Figure 4 Scree Plot - Attitudes



All factor loadings were above 0.400 on only one of the two-factors except for *Women who have undergone FGM/C are empowered agents* which had a factor loading of 0.390 and was retained for the final subscale. The two-factor solution accounted for 37.5% of the total variance. Each item loaded cleanly on one of the two factors, except for *Health care providers should perform reinfibulation (re-closing of the vulvar scar following childbirth) if the woman requests it* which did not load on either factor and thus was dropped. This item likely did not perform well in the EFA because many participants may be unfamiliar with the term *reinfibulation*. See table #6 for the rotated factor loadings for the Attitudes items.

Items loaded according to whether they addressed negative or empathetic attitudes toward FGM/C and those who practice or are affected by FGM/C including the women themselves, their families and communities (further referred to as *Negative Attitudes* and *Empathetic Attitudes* for brevity). The scale names aim to highlight that health care providers

toward FGM/C and the individuals who have undergone FGM/C or perpetuate the practice within families or communities can affect the care that is provided. Each subscale has five items. The correlation between the factors is -0.558 which indicates that the factors have a strong correlation but represent distinct underlying variables that are inversely correlated. The communalities for all items range from 0.173 - 0.624.

Table 6 Rotated Factor Loadings – Attitudes Items

| | <i>Negative Attitudes Toward FGM/C and Those Who Practice FGM/C</i> | <i>Empathetic Attitudes Toward FGM/C and Those Who Practice FGM/C</i> |
|--|---|---|
| FGM/C is a violation of human rights | .593 | -.066 |
| Health Care Providers who perform any form of FGM/C, including symbolic nicking, should be charged with a crime | .455 | -.099 |
| Communities that practice FGM/C are oppressive towards women | .809 | .101 |
| Parents who have their daughter circumcised are abusing them | .804 | .039 |
| Women who have undergone FGM/C are victims of an oppressive cultural practice | .766 | -.041 |
| <i>Symbolic nicking or cutting of the female genitalia is an effective way to reduce the harm of FGM/C compared to more extensive procedures</i> | .024 | .444 |
| <i>Adult women have the right to undergo FGM/C</i> | -.025 | .440 |
| <i>Communities that practice FGM/C are honoring an important cultural tradition</i> | -.028 | .557 |
| <i>Parents who have their daughter circumcised are protecting her future marriage prospects</i> | .043 | .637 |
| <i>Women who have undergone FGM/C are empowered agents</i> | -.044 | .390 |
| Cronbach's Alpha | <i>0.814</i> | <i>0.628</i> |
| DROPPED ITEM | | |
| <i>Health care providers should perform reinfibulation (re-closing of the vulvar scar following childbirth) if the woman requests it</i> | -.121 | .244 |

Principal Axis Factoring. Rotation Method: Oblimin Rotation.

Reliability

We assessed the reliability of the subscales using Cronbach's alpha – a measure of internal consistency of the items as they perform in a specific sample. The *Empathetic Attitudes*

subscale has a Cronbach's alpha of 0.628. This meets the 0.60 threshold considered the minimum acceptable for early stages of research.^{68,69} Further, Cronbach's alpha tends to underestimate the internal consistency of scales with fewer than 10 items such as ours.^{70,71} The *Negative Attitudes* subscale has a Cronbach's alpha of 0.814 which is considered an acceptable level of internal consistency.

Descriptive Statistics

We calculated total scores for each subscale by summing scores for each of the five items. Higher scores indicate more negative attitudes and more empathetic attitudes on each scale respectively. See table #7 for means, standard deviations, minimum and maximum observed scores

**Table 7 Attitudes - Descriptive Statistics
(n=291)**

| | Mean | Std. Dev. | Min | Max | Possible Range |
|---|-------|-----------|-----|-----|----------------|
| <i>Negative Attitudes Toward FGM/C</i> | 15.85 | 2.65 | 10 | 20 | 5-20 |
| <i>Empathetic Attitudes Towards FGM/C</i> | 11.75 | 2.37 | 5 | 20 | 5-20 |

The mean score on the *Negative Attitudes* was 15.85 (SD 2.65) out of 20 indicating that the sample tended to agree or agree strongly with statements that portray FGM/C and those who practice FGM/C negatively. The range of scores for the *Negative Attitudes* subscale was between 10-20 with a roughly normal distribution of scores. The mean score on the *Empathetic Attitudes* was closer to the mid-range of possible scores (11.75, SD 2.37) indicating that participants tended to agree or disagree with the statements, rather than holding strong opinions on either end of the response range. The range of scores for participants on the *Empathetic Attitudes* subscale included the full possible range from 5-20.

Criterion Validity

We assessed criterion validity using independent t-tests to assess hypothesized differences in scores between known groups. There were no significant differences in scores on the *Negative Attitudes* or *Empathetic Attitudes* scales between those who had received training or ever care for patient with FGM/C compared to those without those experiences. Licensed independent providers (MD/ CNM/ NP) had significantly higher scores on the *Negative Attitudes* scale and significantly lower scores on the *Empathetic Attitudes* scale compared with nurses and mental health providers which supports our hypothesis. Scores were not significantly different on either scale for participants with a clinical focus in women's health. Male participants and white participants both had significantly higher scores on the *Negative attitudes* scale which supports our hypotheses; however, there were no significant differences in scores on the *Empathetic Attitudes* scale for either of these two groups. See table #8 for details criterion validity analysis.

Table 8 Criterion Validity – Attitudes
(n=291)

| | | Negative Attitudes | | | Empathetic Attitudes | |
|---------------------------------------|-----|--------------------|-------|--------------|----------------------|--|
| | N | Mean (SD) | p | Mean (SD) | p | |
| PREVIOUS FGM/C EXPERIENCES | | | | | | |
| Ever Cared for FGM/C-Affected Patient | | | | | | |
| - Yes | 128 | 16.05 (2.53) | 0.259 | 11.73 (2.42) | 0.943 | |
| - No | 163 | 15.69 (2.74) | | 11.75 (2.34) | | |
| Received FGM/C Training* | | | | | | |
| - Yes | 101 | 15.75 (2.41) | 0.652 | 11.96 (2.31) | 0.262 | |
| - No | 190 | 15.90 (2.77) | | 11.63 (2.40) | | |
| SCOPE OF PRACTICE | | | | | | |
| Nursing and Mental Health Providers | | | | | | |
| - Yes | 149 | 15.51 (2.77) | 0.031 | 12.19 (2.30) | 0.001 | |
| - No | 141 | 16.18 (2.47) | | 11.30 (2.36) | | |
| Women's Health Specialty* | | | | | | |
| - Yes | 86 | 16.00 (2.35) | 0.512 | 11.74 (2.26) | 0.915 | |
| - No | 189 | 15.79 (2.75) | | 11.78 (2.50) | | |
| DEMOGRAPHIC | | | | | | |
| Gender | | | | | | |
| - Male | 37 | 16.62 (3.06) | 0.050 | 11.22 (2.03) | 0.107 | |
| - Female | 240 | 15.71 (2.55) | | 11.88 (2.37) | | |
| Race | | | | | | |
| - White | 194 | 16.12 (2.65) | 0.014 | 11.57 (2.48) | 0.078 | |
| - Person of Color | 97 | 15.31 (2.59) | | 12.09 (2.12) | | |

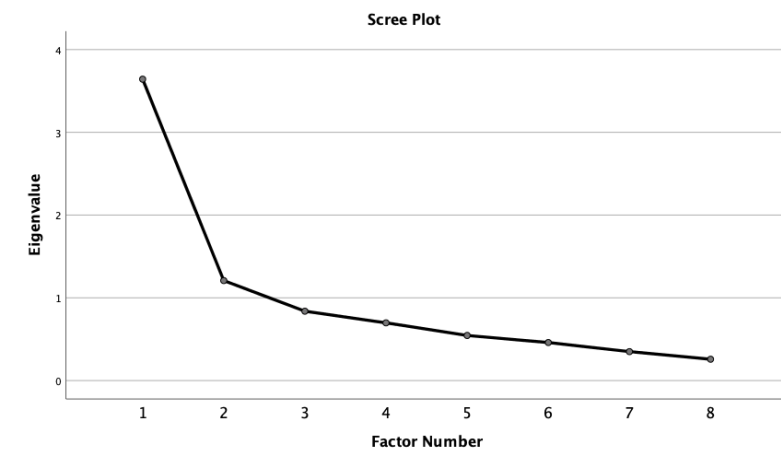
*Unequal variance

Results – Psychometric Testing for Confidence Scale

The psychometric analysis of the Confidence scale includes licensed independent providers (doctors, residents, midwives, and nurse-practitioners). We began the factor analysis by reviewing the cases for completeness which demonstrated 4-9% missing responses per item. We reviewed the item variance and found that *Respond to the health concerns of women with FGM/C by engaging in non-judgmental listening* and *Create a positive therapeutic relationship with a patient who refuses a recommended procedure* had minimal variance with >91% selecting agree or strongly agree. We retained these items for the EFA because they addressed important aspects of quality care related to communication with women and girls who have experienced FGM/C.

The EFA resulted in a 2-factor solution, which accounted for 50.87% of all variance. The eigenvalues (first five were 3.64, 1.21, 0.84, 0.70, 0.55) suggested that the eight items form two factors, which we confirmed using the scree plot to visualize two factors above the break in the plot. See Figure #5.

Figure 5 Scree Plot - Confidence



All items had factor loadings over 0.400 and each item loaded on a single factor. See table #9 for rotated factor loadings for the confidence items. The communalities range from 0.223 – 0.823.

Table 9 Rotated Factor Loadings – Confidence Items

| | Confidence in Clinical FGM/C Care | Confidence in Critical Communication Skills for FGM/C Care |
|---|-----------------------------------|--|
| On inspection of the female genitalia, I can identify a woman with FGM/C | .569 | 0.166 |
| On identification of a woman with FGM/C, I can assign the appropriate WHO Type classification | .970 | -0.185 |
| On identification of a woman with FGM/C, I can appropriately code a visit to document the presence and type of FGM/C using ICD-10 and CPT codes | .736 | -0.064 |
| Counsel women on the possible complications she may experience related to FGM/C | .512 | 0.380 |
| Discuss defibulation with pregnant women who have undergone Type 3 FGM/C in a culturally sensitive manner | .695 | 0.183 |
| Conduct an effective reproductive/sexual health history via an interpreter | 0.285 | .463 |
| Respond to the health concerns of women with FGM/C by engaging in non-judgmental listening | 0.080 | .747 |
| Create a positive therapeutic relationship with a patient who is refuses a recommended procedure | -0.094 | .670 |
| Cronbach's Alpha | 0.857 | 0.694 |

Principal Axis Factoring. Rotation Method: Oblimin Rotation.

The first subscale addresses items related the provision of clinical care of women who have experienced FGM/C, titled “Confidence for Clinical FGM/C Care.” The second subscale includes items that assess the health care provider’s confidence in critical communication skills

for the care of women who have experienced FGM/C titled “Confidence in Critical Communication for FGM/C.”

Reliability

The Cronbach’s alpha coefficient for the two confidence subscales were 0.857 for the “Confidence in Clinical FGM/C Care” and 0.694 for “Confidence in Critical Communication Skills for FGM/C Care” again indicating acceptable levels of reliability.

Descriptive Statistics

We calculated scores for the subscales by summing the scores for each item. The subscale “Confidence in Clinical FGM/C Care” has five items on a four-point Likert scale from strongly disagree=1 to strongly agree=4 for a possible score range of 5-20. The subscale addressing “Confidence in Critical Communication Skills for FGM/C Care” has three items on the same four-point Likert scale for a possible range of 3-12. Higher scores indicate more confidence. The correlation between the two factors is 0.461 which indicates that the subscales are positively correlated but do measure distinct latent constructs. See table #10 for descriptive statistics.

Table 10 Descriptive Statistics – Confidence Scales

| <i>(n=143)</i> | | | | | |
|--|-------------|------------------|-------------------------|------------|------------|
| | Mean | Std. Dev. | Range (possible) | Min | Max |
| <i>Confidence in Clinical FGM/C Care</i> | 11.52 | 2.90 | 5-20 | 5 | 20 |
| <i>Confidence in Critical Communication Skills for FGM/C Care</i> | 9.08 | 1.35 | 3-12 | 3 | 10 |

The mean score on the *Clinical FGM/C Care* subscale (11.52) indicating that participants generally endorsed a moderate level of confidence in their ability to provide clinical care for women and girls affected by FGM/C. The distribution of scores on the *Clinical FGM/C Care*

subscale is approximately normally distributed with slightly more participants reporting lower levels of confidence. The mean score on the *Critical Communication Skills for FGM/C Care* subscale (9.08) indicates somewhat higher confidence in communication skills compared to clinical skills for FGM/C. The distribution of scores for the *Critical Communication Skills for FGM/C Care* scores is approximately normally distributed.

Criterion Validity – Confidence Scales

We assessed criterion validity using independent t-tests to assess differences in scores between known groups. Health care providers who had ever cared for someone affected by FGM/C, had ever received FGM/C training, whose scope of practice includes a women's health specialty, people of color, and women rated their *Confidence in Clinical FGM/C Care* significantly higher than the comparison groups. Health care providers who have ever cared someone who had experienced FGM/C and those with a scope of practice focused on women's health had significantly high scores on the *Confidence in Critical Communication Skills for FGM/C Care* scales than the comparison groups. There was no significant difference in *Confidence in Critical Communication* scores for those who had received previous training related to FGM/C. See table #11.

**Table 11 Criterion Validity – Confidence Subscales
(n=143)**

| | | Confidence in Clinical FGM/C Care | | Confidence in Critical Communication Skills for FGM/C Care | |
|---------------------------------------|----|-----------------------------------|-------|--|-------|
| | N | Mean (SD) | p | Mean (SD) | p |
| PREVIOUS FGM/C EXPERIENCES | | | | | |
| Ever Cared for FGM/C-Affected Patient | | | | | |
| - Yes | 99 | 12.51 (2.59) | 0.000 | 9.32 (1.23) | .001* |
| - No | 44 | 9.27 (2.25) | | 8.53 (1.47) | |
| Received FGM/C Training | | | | | |
| - Yes | 64 | 12.32 (2.38) | 0.002 | 9.20 (1.29) | .347 |
| - No | 79 | 10.88 (3.12) | | 8.99 (1.40) | |
| SCOPE OF PRACTICE | | | | | |

| | | | | | |
|---------------------------------|----|--------------|--------|-------------|-------|
| <i>Women's Health Specialty</i> | | | | | |
| - Yes | 74 | 12.42 (2.58) | >0.000 | 9.35 (1.27) | .010* |
| - No | 62 | 10.34 (2.81) | | 8.76 (1.39) | |

*Statistically Significant <0.05

Discussion

In this study, we have constructed measures of health care provider attitudes and confidence for the care of women and girls affected by FGM/C and assessed their validity and reliability. Our new measures of health care provider attitudes and confidence for the care of FGM/C-affected patients represent an important step forward in the assessment of health care providers. We utilized a conceptual approach to our item development by first defining attitudes and confidence, and then framing which types of attitudes (negative and empathetic), and confidence (clinical skills and communications skills) were important when considering their effect on quality of care based on review of qualitative studies and existing measures. Our attitudes scales include some items that are similar to existing measures (harm reduction, adult women's right to FGM/C, human rights) and add novel items to assess attitudes towards communities that practice FGM/C and affected patients.

The psychometric properties of the Confidence subscales were strong overall. The subscales have a clear factor structure, and acceptable reliability. The validity of the Confidence for Clinical FGM/C Care is supported by the significance of the hypothesized group differences. The validity for the *Confidence in Critical Communication Skills for FGM/C Care* is supported by the significance of two of three hypothesized group differences. While we did not find a significant difference in confidence scores for those with and without previous FGM/C training in the *Confidence in Communication* subscale, this could potentially be a result of training programs focusing more on clinical skills than communication skills. There is very limited

published data on existing trainings for FGM/C, and none we reviewed evaluated training effectiveness to improve communication skills.

The Attitudes subscales also have clear factor structures, and the reliability of the Negative Attitudes subscale is acceptable. The reliability of the Empathetic Attitudes subscale falls just below the acceptable threshold. Cronbach's alpha measures have some limitations -they measure the internal consistency of the items within a specific sample, where more heterogeneous populations tend to increase the Cronbach's alpha. Given that our sample was self-selected, they may be more homogeneous and positive in terms of attitudes toward FGM/C compared to the general population of health care providers. Our subscales also have a relatively small number of items (<10), which can also lower the alpha estimate. The reliability of the scales should be further assessed in a random sample of health care providers. Future research should further assess the reliability of these scales with a diverse study population that varies in relation to demographic variables such as race, gender, and political affiliation; travel experience; and whether FGM/C has been practiced within their family or close contacts. Further validation of the scale could also include assessment of concurrent validity. Though there are no validated measures of attitudes related to FGM/C, comparing participants' scores on our scale with scores on validated measures of empathy and implicit bias may further inform the validity of the attitude scales.

There are some important differences between our scale and existing measures. We did not include items that assessed whether participants believe FGM/C is a religious practice or whether they knew their legal or reporting requirements because these questions address knowledge rather than attitudes.^{7,60} Our confidence scales included some similar concepts compared to existing measures including items addressing identification and documentation of

FGM/C; however, our scales included more items regarding communication and counseling skills.^{54,57} Our scales are consistent with existing measures for attitudes and confidence by including items about defibulation and reinfibulation.^{50,54,58}

Within the US, many women and girls affected by FGM/C are migrants or refugees from Africa, Asia, or the Middle East who may have low-English proficiency – all variables that may contribute to experiences of bias, discrimination, and lower quality of care. The historical legacy of slavery and racism in the US, and in particular the “othering” of African women’s bodies, may implicitly influence the patient-provider interaction, counseling and decision-making.²⁴ Health care providers must take responsibility for communicating attitudes that promote positive patient/provider interaction so that FGM/C affected patients do not experience bias or discrimination during a clinical encounter. Our scales are an important step to assess health care provider attitudes toward FGM/C and those affected by the practice, and eventually to explore how their attitudes are related to patient experiences of care. The new attitudes scales may allow researchers and educators to explore whether health care providers who experience more empathic and less negative attitudes provide higher quality care to patients affected by FGM/C. While empathy does tend to improve patient-provider communication, it is important to assess if health care provider empathy moves toward endorsement of harm reduction approaches to addressing FGM/C versus elimination of the practice.⁷² Some health care providers maintain that the less extensive forms of FGM/C, such as symbolic nicking, should be permitted in place of more extensive cutting to minimize harm.^{72–74} A recent case in Michigan where a doctor allegedly performed type 1 FGM/C in a clinic illustrates that FGM/C diaspora communities and health care providers are negotiating these tensions within the US.⁷⁵ By including items that assess strongly empathetic attitudes toward FGM/C, researchers and educators may be able to

provide additional education to health care providers regarding the physical and ethical harm of cutting the genital of a minor. Some argue that minors (child with male, female, or intersex genitalia) must be protected from bodily harm, which includes nontherapeutic genital surgery or cutting (including male circumcision).⁷⁶ Though these attitudes may be less common in the US, our scales may detect the range of empathetic attitudes. It is important to note that this measure assesses attitudes, and not intent.

In our study sample, previous training in FGM/C was not a statistically significant predictor of increased *Confidence in Communication for FGM/C*. This may be because existing FGM/C trainings do not focus on communication skills, or if they do, may not provide an opportunity to practice those skills in order to measurably improve provider confidence.⁷⁷ Future trainings should include informational content about FGM/C (history and context, identification, documentation, complications, and management for patients affected by FGM/C) to build provider confidence in their knowledge to provide clinical care for FGM/C. Trainings should include opportunities for simulation, reflection, and engagement to practice applying knowledge, communications skills (including interpreter use), and build awareness of how their attitudes may affect the quality of care delivered to those affected by FGM/C.⁷⁵ Broad health workforce education to improve the care of patients affected by FGM/C, including effective evaluation of education and training interventions, is an important public health priority.⁷⁵

Some limitations of our study include geographic restriction of the study population to the greater Phoenix, Tucson, and Baltimore areas and a low response rate by the study population. We used a convenience sample for this analysis with participants who self-selected to register and complete the survey for an FGM/C training workshop, which could result in a bias related to their interest in the topic of FGM/C. Future studies may expand the geographical

area of the study population and different recruiting methods to reduce bias. As discussed previously, the *Empathetic Attitudes* subscale did not have strong reliability as measured by Cronbach's alpha. A future iteration of the *Empathetic Attitudes* scale with additional items in a random sample of health care providers may remedy this issue. Our study could have been strengthened by assessing concurrent validity of our subscale using a criterion measure; however, we were not able to identify any validated attitudes or confidence scales to use.

Conclusion

To the best of our knowledge, our attitude and confidence scales presented here are the first psychometrically validated measures to assess health care provider attitudes and confidence in the care of women and girls affected by FGM/C. Our confidence scales have strong validity and reliability, our attitudes scales have a clear factor structure, and the *Negative Attitudes* scale has strong reliability. Researchers may explore the relationship between health care provider attitudes and confidence for FGM/C related care with patient outcomes such as patient perceptions of quality of care (including experiences stigma and/or bias), trust in their provider, and receipt of appropriate diagnosis and treatment of FGM/C and associated health complications. Our measures will support future researchers to investigate factors that affect quality of care for women and girls who have experienced FGM/C.

Declarations

Ethics Approval and Consent to Participate

This analysis includes a combined data set reflecting the locations where we conducted health care provider trainings (Arizona and Maryland). We received approval from the Arizona State University Institutional Review Board (IRB), and the Johns Hopkins Medical Institute IRB. Participation was voluntary and anonymous. No incentives were offered.

Consent for Publication

Not applicable

Availability of Data and Materials

The datasets used and analyzed during the current study are available from the corresponding author on reasonable request.

Competing Interests

The authors declare that they have no competing interests.

Funding

This study was funded by a grant from The Department of Health and Human Service/Office on Women's Health (grant number # ASTWH160045-02-00), and the Rockefeller University Heilbrunn Family Center for Research Nursing through the generosity of the Heilbrunn Family.

Authors' Contributions

CXM is the main researcher who designed the study and led the writing process. CXM and CJA conducted data collection. CXM and NP performed the data analysis. CJA, NP, NW, and NG contributed to the conceiving of the study, the data analysis and writing process. All authors read and approved the final manuscript.

Acknowledgements

We thank Karoun H. Bagamian for her writing and editorial suggestions.

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CHAPTER 3: MANUSCRIPT TWO

Factors Associated with Health Care Provider Awareness, Attitudes, and Confidence for the Care of Women and Girls Affected by FGM/C

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Proposed Journal: BMC Public Health

Date of Submission: *pending*

Abstract

Background: Health care providers in the USA often lack awareness about FGM/C and its complications, lack confidence in their ability to provide appropriate FGM/C-related care, and experience attitudes towards FGM/C that may negatively impact quality of care. Women affected by FGM/C receiving care in the diaspora are aware of these deficits which result in a distrust of health care providers, and fear and anxiety accessing the health care system. Women affected by FGM/C report experiencing stigma and bias related to their FGM/C status.

Methods: We conducted a cross-sectional baseline survey of health care providers in Phoenix and Tucson, Arizona and Baltimore, Maryland areas. Following a summary of descriptive statistics of demographics and previous FGM/C-related clinical experience, we performed multivariable analysis to explore the associations between health care provider awareness of health complications of FGM/C, and scales on validated measures for *Confidence for Clinical FGM/C Care*, *Confidence in Critical Communication Skills for FGM/C Care*, *Negative Attitudes toward FGM/C* and *Empathetic Attitudes Toward FGM/C*.

Results: Health care providers were aware of a median of 25 of 33 health complications associated with FGM/C. Factors associated with increased awareness of health complications included having ever care for a woman with FGM/C or ever having received FGM/C training. Participants scored toward the higher end of the *Negative Attitudes* scale (mean – 16.4, possible range 5-20), while scores on the *Empathetic Attitudes* fell around the middle range (mean – 11.24, possible range 5-20). The only statistically significant factor associated with either attitudes score was women had significantly less *Negative Attitudes* toward FGM/C compared with men. Participants scored an average of 11.48 (possible range 5-20) on the *Confidence for Clinical FGM/C Care* scale indicating a moderate level of confidence, while they scored an average of 9.08 (possible range 3-12) indicating higher *Confidence in Critical Communication Skills for FGM/C Care* scale. Factors associated with higher *Confidence for Clinical FGM/C Care* scores include more awareness of health complications, having ever cared for a woman with FGM/C, being a woman, identifying as a person of color, and more than 5 years in clinical practice. The only factor associated with increased *Confidence in Critical Communication Skills for FGM/C Care* was higher levels of awareness of health complications for FGM/C.

Conclusion: Health care providers would be well served by comprehensive training for the care of women and girls affected by FGM/C. Future trainings should include didactic content that address the potential health complications of FGM/C, as well as opportunities to explore their attitudes toward FGM/C and those who practice FGM/C and to build confidence in their clinical and communications skills to care for this underserved population.

Trial Registration: Clinical Trials.Gov ID # NCT03249649, Study ID# 5252. Public website: <https://clinicaltrials.gov/ct2/show/NCT03249649>

Key Words: Female Genital Cutting, Female Genital Mutilation, Female Circumcision, Health Care Provider, Attitudes, Confidence

Introduction

Female Genital Mutilation/Cutting (FGM/C) includes procedures that intentionally alter or cause harm to female genital organs for non-medical reasons and affects approximately 200 million women and girls globally.⁷⁸ FGM/C is practiced in 30 countries with the majority in Sub-Saharan Africa, and others in the Middle East and South Asia.^{1,3} Although FGM/C prevalence rates are falling globally, the number of girls and women affected will rise in coming decades because of persistently high fertility rates in FGM/C practicing countries.¹ The COVID emergency is currently contributing to a rise in cutting in some regions, with an estimated additional 2 million girls at risk for FGM/C.⁷⁹ In the United States of America (USA), the Centers for Disease Control (CDC) estimates that 545,000 women and girls may have undergone FGM/C or been born to women from FGM/C-practicing countries.³¹ This latter group is often assumed to be at-risk for FGM/C. Health care providers in countries where FGMC is not normative are increasingly likely to care for affected women and girls due to global migration trends and must be able to meet the health care needs of this group.¹

FGM/C is conducted on girls between infancy and adolescence, usually by the age of 15, and may include practices from a symbolic nicking of the clitoris to infibulation (cutting and sewing a narrowed vaginal opening) depending on the region and cultural group.¹ FGM/C is primarily conducted by non-medical providers, such as traditional birth attendants, although there is a trend toward medicalization (when FGM/C is performed by a health care provider).⁸⁰ All types of FGM/C have been associated with adverse health consequences including, adverse immediate, gynecologic, obstetric, mental and sexual health outcomes; however, not all women with FGM/C will experience adverse health effects, and more severe morbidity is associated with more extensive forms of cutting.^{2,14} Women and girls who have experienced FGM/C require

specialized health care to address the possible health complications.^{12–18} For women with Type 3 FGM/C, *defibulation*, or the surgical release of the FGM/C scar to widen the vaginal open, is an important intervention that can lessen or eliminate some health complications of FGM/C and prevent some complications of childbirth associated with FGM/C.⁸¹ However, health care providers rarely receive training for the care of women and girls who have experienced FGM/C,^{4,6–10} and obstetric providers rarely receive training to perform defibulation.⁵⁰ In the US and other Western countries, health care providers may find themselves facing ethical dilemmas as they balance an opposition to FGM/C as a practice with adult women's right to bodily modifications. A recent survey of obstetric providers in the US found that approximately 30% would perform reinfibulation, a type of FGM/C that includes the partial or complete re-suturing of the vulva following defibulation, if a woman requested it.⁵⁰ Those providers who have received training often report that they would benefit from additional training.^{7,53,82,83}

WHO defines quality care as being effective, efficient, accessible, patient-centered, equitable, and safe.²⁵ Although there are guidelines available for the care of women and girls affected by FGM/C from the World Health Organization (WHO), and professional and advocacy groups, the health outcomes and experiences of FGM/C affected populations receiving care in the diaspora are poor.^{2,30} Caesarean births rates are elevated for non-obstetric reasons;^{84,85} women report fear of and a lack of trust in their health care providers;^{37,47} women experience barriers to care that result in delays;⁴⁹ they are less likely to access preventative health services;⁴⁹ and they experience disrespect and stigma in the health care setting.³⁹ Women and girls may not report FGM/C or associated symptoms because of negative attitudes of health care providers, or because they may not realize the symptom may be related to their FGM/C status.^{41,43} The lack of health care provider awareness about the health consequences of FGM/C further degrades quality

of care.¹¹ In order to provide quality care for FGM/C, health care providers must be aware of the potential health complications of FGM/C, be confident in their ability to manage care for women and girls who have experienced FGM/C, and understand how their own attitudes toward FGM/C and those affected by the practice may impact how they provide care.

Conceptual Approach

The *Knowledge, Attitudes, and Practices (KAP)* framework is often used to assess health care providers who care for women and girls affected by FGM/C; however, we were not able to identify any validated measures for FGM/C.⁴ The KAP framework theorizes that an individual learns about a topic (knowledge), develops some affective response (attitude), and engages in a behavior (practice) – often these factors influence one another in multidirectional ways.⁸⁶ Existing studies assessing health care providers’ knowledge, attitudes, and practices have typically reported their results as purely descriptive, without exploring the relationships between knowledge, attitudes and practices or considering health care provider characteristics, such as demographics or past experiences with FGM/C, as confounders to these relationships.^{4,26}

Purpose

The goal of this study is to describe and explore the relationship between provider characteristics, awareness of the health complications of FGM/C (knowledge), attitudes toward FGM/C, and confidence in the ability to care for patients affected by FGM/C (practice). We elected to measure health care provider awareness of health complications because an important reason that FGM/C is opposed is because of the harm that it causes in the form of adverse health complications. Self-reported confidence is a proxy for practice when we cannot directly observe provider care.⁶⁶ A more rigorous examination of providers’ awareness, attitudes and confidence

will provide a clearer direction for the FGM/C related training and education that providers indicate they desire.

Methods

Study Setting

We conducted an online cross-sectional survey of health care providers at the time of registration in a workshop titled “Optimizing Care for Women and Girls Affected by FGM/C” in the greater Phoenix and Tucson, Arizona and Baltimore, Maryland areas. This survey was embedded into a larger program funded by the Department of Health and Human Service/ Office on Women’s Health (grant number # ASTWH160045-02-00) whose primary aim was to enhance culturally-informed health care services for women affected by FGM/C.

Recruitment and Study Population

Health care providers were invited to participate via an email invitation to a workshop and/or grand rounds presentation on FGM/C between September 2016 – May 2017 for Phoenix and Tucson, Arizona and in September-October 2018 for the greater Baltimore, Maryland areas. Participants were recruited via email to hospital department chairs, residency program directors, medical directors, nursing and medical faculty, and professional organizations who then shared the email invitations via their list-servs. Emails included a registration link, and an invitation to complete the survey. Emails were distributed to list-servs at 14 health care institutions in Phoenix and Tucson, Arizona, and broadly distributed within the Johns Hopkins Health System and Johns Hopkins University Schools of Medicine, Nursing and Public Health as well as to professional organizations in the greater Baltimore, Maryland and Washington D.C. area. Email

invitations to the workshop were sent at three time points starting 1-month prior to the respective event.

The Greater Baltimore area is home to large populations of migrants from Sudan, Ethiopia and Eritrea, while Arizona has received a large number of Somali refugees.^{87,88} These countries have high FGM/C prevalence (74-98%), and FGM/C type in these countries tends to be Type 3 – the most extensive form of cutting with the highest rate of morbidity.¹

Measures

The online questionnaire included four sections: clinician characteristics (demographics, scope of clinical practice, and previous clinical experiences related to FGM/C), awareness of health complications of FGM/C, attitudes toward FGM/C, and confidence in providing care for women with FGM/C. Providers self-report of race and ethnicity was recorded as Black, Hispanic/ Latino, Asian, Native American/ Indigenous, or Other Non-White.

The attitudes and confidence measures were developed and validated by our research team – the psychometric validation of the attitudes and confidence scales are presented in a separate manuscript. We measured awareness of health complications of FGM/C by asking respondents to note which of 33 possible health complications associated with FGM/C they were aware of prior to seeing the list. The 33-item checklist, based on the health complications of FGM/C identified by the 2016 WHO Guidelines, were sorted into five areas including immediate post-FGMC, obstetric, gynecologic, sexual, and psychological.² The final score of awareness is the number of items checked. The Attitudes measure includes two subscales “Negative Attitudes toward FGM/C and Those Affected by the Practice” (referred to henceforth as *Negative Attitudes* scale) and “Empathetic Attitudes toward FGM/C and Those Affected by the Practice” (referred to henceforth as *Empathetic Attitudes* scale). The Attitudes measures include items that assess

attitudes towards not just FGM/C, but also towards those affected by the practice including women who have undergone FGM/C and families and communities that continue to practice FGM/C. The Confidence measure also includes two subscales “Confidence in Clinical FGM/C Care” and “Confidence in Critical Communication Skills for FGM/C Care.” The attitudes and confidence scales both have Likert response options from 1=strongly disagree, 2=disagree, 3=agree and 4=strongly agree. *See table #12 for sample items from each measure and Cronbach’s alphas.*

Table 12 Attitudes and Confidence Scale Characteristics and Sample Items
SCALE NAMES AND EXAMPLE ITEMS

| | Cronbach’s Alpha | Number of Items |
|---|-------------------------|------------------------|
| <i>Negative Attitudes toward FGM/C and those affected by the practice</i> | 0.814 | 5 |
| Health Care Providers who perform any form of FGM/C, including symbolic nicking, should be charged with a crime | | |
| <i>Empathetic Attitudes toward FGM/C and those affected by the practice</i> | 0.628 | 5 |
| Symbolic nicking or cutting of the female genitalia is an effective way to reduce the harm of FGM/C compared to more extensive procedures | | |
| <i>Confidence in Clinical FGM/C Care (5 items)</i> | 0.857 | 5 |
| On inspection of the female genitalia, I can identify a woman with FGM/C | | |
| <i>Confidence in Critical Communication Skills for FGM/C Care</i> | 0.694 | 3 |
| Respond to the health concerns of women with FGM/C by engaging in non-judgmental listening | | |

Statistical Analysis

We analyzed data using SPSS (version 26) for statistical analysis. This analysis includes a combined data set reflecting the locations where we recruited participants (Arizona and Maryland). The number of valid and missing responses are noted in the demographic and regression tables. We addressed missing data in scale scores using replacement for the average for any participants who had completed at least 75% of the items for the 5 item scales, and 66% of the items for the 3-items scales. Descriptive statistics are presented as count and percentages. We used multivariable linear regression to explore variables associated with attitudes and

confidence in order to understand what provider characteristics are associated with different levels of confidence, and more or less negative and empathetic attitudes. We used Poisson regression to explore variables associated with the number of health complications of FGM/C a provider is aware of in order to explore provider characteristics associated with more awareness of the health complications of FGM/C. We examined participant characteristics (women's health clinical specialty, years of experience dichotomized as <5 years or 5 years or more, gender, and race dichotomized as person of color or white) and previous FGM/C experiences (having ever cared for a woman who had experienced FGM/C, ever received training for the care for women who have experienced FGM/C) as covariates.

Ethics Statement

We received approval from the Arizona State University Institutional Review Board (IRB), and the Johns Hopkins Medical Institute IRB. Participation was voluntary and anonymous. No incentives were offered for participating in the study. Electronic consent was obtained from all participants prior to accessing the on-line survey.

Results

Participant Characteristics

A total of 796 individuals attended training events in Arizona and 101 in Maryland for a total of 897 possible survey participants. A total of 354 participants completed the online survey for a response rate of 39.5%, of whom n=164 were physicians or medical residents, nurse-practitioners or nurse-midwives. The remaining 190 survey participants were medical and nursing students, nurses, mental health providers, social workers, and other public health workers.

Participants for this analysis were predominantly physicians (28%) or resident physicians (48.8%), female (73.2%), and white (76.8%). About half the sample specialized in women's health (47%), and the majority had less than 5 year of clinical experience (62.2%). See table #13 for detailed participant characteristics.

Table 13 Participant Characteristics
(n=164)

| | Combined N (%) |
|--|-------------------|
| Clinical Practice | |
| - Outpatient Medical Care | |
| - Resident | 80 (48.8) |
| - Physician | 46 (28.0) |
| - CNM | 28 (17.1) |
| - NP | 10 (6.1) |
| Gender | |
| - Female | 120 (73.2) |
| - Male | 33 (20.1) |
| - Missing/ Declined/ Other/ Trans | 11 (6.7) |
| Race/ Ethnicity | |
| - Person of Color | 37 (22.6) |
| - Latino/ Hispanic | 11 (6.7) |
| - Asian | 16 (9.8) |
| - Black/ African American/ Native American/ Other Non-White* | 10 (6.1) |
| - White | 126 (76.8) |
| - Missing/ Declined | 1 (0.6) |
| Women's Health Specialty | |
| - Yes | 77 (47.0) |
| - No | 79 (48.2) |
| - Missing | 8 (4.9) |
| Scope of Practice includes BIRTH (Ob/Gyn, Midwife) | |
| - Yes | 76 (46.3) |
| - No | 80 (48.8) |
| - Missing | 8 (4.9) |
| Years in Practice | |
| < 5 | 102 (62.2) |
| 5-10 | 22 (13.4) |
| 10-20 | 16 (9.8) |
| >20 | 23 (14.0) |
| Missing/ Declined | 1 (0.6) |

*Due to small n in these groups, they were collapsed to protect participant confidentiality

Most participants had previously cared for a patient with FGM/C (65.9%), though less than half had received training in how to care for women affected by FGM/C (41.5%). Just over half were aware of the WHO FGM/C type system (55.5%), and two-thirds (64%) were aware of defibulation. There were no significant differences in these experiences by site. See table #14.

Table 14 Participant Experiences with FGM/C
(n=164)

| | Combined N (%) |
|--|-------------------|
| Ever Cared for Patient with FGM/C | |
| - Yes | 108 (65.9) |
| - No | 56 (34.1) |
| Previous FGM/C Training | |
| - Yes | 68 (41.5) |
| - No | 96 (58.5) |
| Aware of Defibulation? | |
| - Yes | 105 (64.0) |
| - No | 59 (36.0) |

Health Care Provide Awareness, Attitudes and Confidence for FGM/C

Participants were asked to indicate which of the FGM/C complications they were aware of prior to participating in the study. *See Figure #6 for all Health Complications of FGM/C Listed and frequencies selected by study participants.*

Figure 6 Awareness of Health Complications of FGM/C



**n=161, 3 participants did not complete any items for this scale*

Health care providers in our sample were aware of most of the 33 FGMC-related complications (median=25, IQR 17.5 - 30). Participants were aware of a median of 9 (IQR 7-10) out of ten possible immediate complications. Nearly all (91.9%) were aware that FGM/C can cause pain, while about two-thirds were aware that FGM/C can result in shock (64.6%) or death (66.5%). Respondents were aware of a median of 6 (IQR 3-8.5) out of ten possible obstetric complications. The largest proportion of participants were aware that FGM/C is associated with

increased use of episiotomy (71.4%), while the smallest were aware that FGM/C was associated with increased rates of neonates who require resuscitation at delivery (28.0%). Participants were aware of an average of 3.71 (SD 1.73) of 5 possible sexual complications with most aware that FGM/C is associated with pain with sex (83.2%) and the fewest aware that FGM/C is associated with decreased lubrication during intercourse (57.1%). Participants were aware of a median of 3 (IQR 3-3) of 3 possible mental health complications with approximately 80% aware that FGM/C is associated with increased rates of depression, anxiety and PTSD. Participants were aware of a median of 4 (IQR 2-5) of 5 longer term gynecologic complications with most participants aware that FGM/C is associated with chronic vulvar and clitoral pain (86.3%), and the fewest aware that FGM/C is associated with dysmenorrhea (47.2%).

Participants scored an average of 16.21 on the *Negative Attitudes* scale indicating that participants tended to agree or strongly agree with statements endorsing more negative attitudes toward FGM/C, those who are affected, and those who practice it. The minimum score reported was 10 out of a possible 20, which means that no participants strongly disagreed with all statements. Participants scored an average of 11.28 on the *Empathetic Attitudes* scale which represents the middle range of possible scores and may suggest ambivalence toward the statements endorsing empathetic attitudes. There were few participants whose scores fell at the extremes of the scale. Participants scored an average of 11.38 on the *Confidence for Clinical FGM/C Care* scale indicating a moderate level of confidence in participant abilities to provide appropriate clinical care for women affected by FGM/C. Participants scored an average of 9.02 on the *Confidence in Critical Communication Skills for FGM/C Care* scale. Participants tended to have a higher level of confidence in their communication skills for women affected by FGM/C

compared to their clinical skills. See table #15 for descriptive statistics for the attitudes and confidence subscales.

Table 15 Attitudes and Confidence Scales - Descriptive Statistics

| | n | Mean | Std. Dev. | Min | Max | Possible Range |
|---|-----|-------|-----------|-----|-----|----------------|
| Health Care Provider Attitudes Toward FGM/C and those who practice FGM/C | | | | | | |
| Negative attitudes toward FGM/C and those who practice | 154 | 16.21 | 2.40 | 10 | 20 | 5-20 |
| Empathetic attitudes towards FGM/C and those who practice | 150 | 11.28 | 2.33 | 5 | 20 | 5-20 |
| Health Care Provider Confidence for the Care of Women Affected by FGM/C | | | | | | |
| Confidence for Clinical FGM/C Care | 155 | 11.38 | 2.98 | 5 | 20 | 5-20 |
| Confidence in Critical Communication Skills for FGM/C Care | 157 | 9.02 | 1.44 | 3 | 12 | 3-12 |

Relationship between Awareness, Attitudes and Confidence

We explored factors associated with more awareness of health complications of FGM/C using multivariable analysis. All covariables were included in each model. Participants who had ever cared for a woman affected by FGM/C or ever received training for the care of women affected by FGM/C were aware of significantly more health complications of FGM/C than those without those experiences. Clinical practice in women's health, female gender, identifying as a person of color and years' experience were not associated with significantly increased awareness of health complications. *See table #16.*

Table 16 Factors Associated with Awareness of Health Complications of FGM/C – Multivariable Analysis (n=144)*

| | B | 95% CI | p-value |
|--|--------|----------------|---------------|
| Women's Health Focused Clinician | 0.042 | -0.040 – 0.125 | 0.314 |
| Ever Care for a Woman Affected by FGM/C | 0.162 | 0.069 – 0.255 | 0.001* |
| Ever Received Training for Care of Women Affected by FGM/C | 0.093 | 0.020 – 0.167 | 0.013* |
| Female Gender | 0.037 | -0.057 – 0.131 | 0.437 |
| Person of Color | 0.000 | -0.084 - 0.083 | 0.992 |
| More than 5 years Clinical Experience | -0.028 | -0.101 – 0.045 | 0.450 |

*Participants who were missing one of more of the predictor variables were excluded from the analysis

We explored factors associated with increased health care provider confidence for the care of women affected by FGM/C. Factors associated with increased health care provider scores on the *Confidence for Clinical FGM/C Care* include being aware of more health complications of

FGM/C, having ever cared for a woman affected by FGM/C, identifying as female, identifying as a person of color, and having more than 5 years clinical experience. Neither having received previous training for FGM/C nor being a women's health care provider were significantly associated with higher scores for *Confidence for Clinical FGM/C Care*. The only factor significantly associated with higher scores on the *Confidence in Critical Communication Skills* scores was awareness of more health complications of FGM/C.

Table 17 Factors Associated with Health Care Provider Confidence – Multivariable Analysis

| | Confidence for Clinical FGM/C Care (n=139)* | | | Confidence in Critical Communication Skills for FGM/C (n=140)* | | |
|--|--|----------------|------------------|--|----------------|--------------|
| | B (S) | 95% CI | p-value | B (S) | 95% CI | p-value |
| <i>Awareness of Health Complications</i> | 0.265 | 0.047 – 0.140 | <0.001 | 0.187 | 0.002 – 0.059 | 0.035 |
| <i>Women's Health Provider Ever Care for a Woman Affected by FGM/C</i> | 0.089 | -0.365 – 1.389 | 0.249 | 0.074 | -0.333 – 0.733 | 0.459 |
| <i>Ever Received Training for Care of Women Affected by FGM/C</i> | 0.340 | 1.145 – 3.103 | <0.001 | 0.142 | -0.181 – 1.002 | 0.172 |
| <i>Female Gender</i> | 0.066 | -0.408 – 1.182 | 0.338 | -0.012 | -0.515 – 0.450 | 0.894 |
| <i>Person of Color</i> | 0.178 | 0.320 – 2.265 | 0.010 | -0.110 | -0.625 – 0.559 | 0.755 |
| <i>More than 5 years Clinical Experience</i> | 0.161 | 0.242 – 2.029 | 0.013 | 0.026 | -0.459 – 0.631 | 0.755 |
| | 0.135 | 0.037 – 1.607 | 0.040 | 0.034 | -0.383 – 0.571 | 0.696 |

*Participants who were missing one of more of the predictor variables were excluded from the analysis

Next we explored participant characteristics associated with attitudes toward FGM/C and those affected by the practice. Women had significantly lower scores on the *Negative Attitudes* scale compared with men. No other factors were significantly associated with negative attitudes scores. We did note that those who had ever received training for FGM/C care and those who identify as a person of color tended to have lower scores on the negative attitudes scale than their counterparts; however, none of these were significant. Only one factor (more than 5 years clinical experience) had a significant associated with scores on the *Empathetic Attitudes* scale. Participants with more than 5 years of clinical experience has significantly *less* empathetic

attitudes towards FGM/C compared with participants who had less than 5 years clinical experience. *See table #18 for detailed results of the multivariable regression.*

Table 18 Factors Associated with Health Care Provider Attitudes – Multivariable Analysis

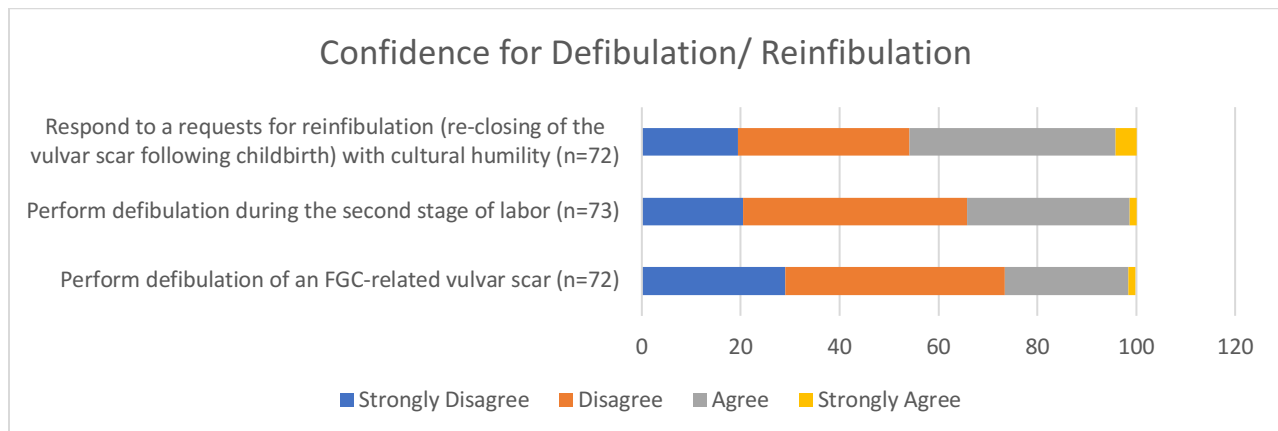
| | <i>Negative Attitudes (n=138)*</i> | | | <i>Empathetic Attitudes N=134)*</i> | | |
|--|------------------------------------|-----------------|---------------|-------------------------------------|-----------------|--------------|
| | B | 95% CI | p-value | B | 95% CI | p-value |
| Awareness of Health Complications | 0.037 | -0.039 – 0.060 | 0.674 | 0.067 | -0.031 – 0.070 | 0.452 |
| Women’s Health Focused Clinician | 0.033 | -0.790 – 1.093 | 0.751 | 0.051 | -0.734 – 1.219 | 0.624 |
| Ever Care for a Woman Affected by FGM/C | 0.084 | -0.618 – 1.445 | 0.429 | 0.088 | -0.618 – 1.510 | 0.409 |
| Ever Received Training for Care of Women Affected by FGM/C | -0.160 | -1.589 – 0.092 | 0.080 | 0.119 | -0.310 – 1.455 | 0.201 |
| Female Gender | -0.234 | -2.380 – -0.332 | 0.010* | 0.060 | -0.727 – 1.448 | 0.513 |
| Person of Color | -0.109 | -1.586 – 0.337 | 0.201 | 0.067 | -0.598 – 1.376 | 0.437 |
| More than 5 years Clinical Experience | 0.036 | -0.654 – 1.005 | 0.677 | -0.180 | -1.776 – -0.039 | 0.041 |

*Participants who were missing one of more of the predictor variables were excluded from the analysis

Defibulation/ Reinfibulation

We performed descriptive analyses of items related to defibulation and reinfibulation among health care providers who attend births including obstetrician/ gynecologists, obstetrician/ gynecologist residents, and nurse-midwives (n=76). Only 8 (10.5%) providers responded that they had been trained to perform defibulation. Almost half of those who attend births (42.1%) agreed or strongly agreed that health care providers should perform reinfibulation if the woman requests it. Health care providers attending births were also asked to rate their confidence related to defibulation and reinfibulation. See figure #7.

Figure 7 Confidence for Defibulation/ Reinfibulation



About a third of health care providers who attend births agreed or strongly agreed that they can perform defibulation during the second stage of labor (35.3%). About a quarter agree or strongly agree that they can defibulate an FGM/C-related vulvar scar (26.4%). This difference may reflect a difference in scope of practice because midwives are less likely to perform antenatal defibulation, which is usually performed in an operating room. Fewer than half of respondents (45.9%) agreed or strongly agreed that they could respond to a request for reinfibulation with cultural humility illustrating that discussions around reinfibulation remain challenging for most health care providers.

Discussion

This study provides the first exploration of the relationship between health care provider characteristics, awareness of health complications, attitudes toward FGM/C, and confidence for FGM/C care using psychometrically validated scales. Existing studies assessing health care providers caring for women and girls affected by FGM/C tend to report descriptive findings, without exploring how these factors are interrelated. Our study sample includes a diverse cross-section of health care providers including physicians, nurse-practitioners, and nurse-midwives who practice in regions with considerable numbers of refugees and immigrants from regions

where FGM/C is common. Of the providers we surveyed, two-thirds had ever cared for a patient with FGM/C but fewer than half had received any training for the care of those affected by FGM/C. This is consistent with a recent US survey of obstetric providers which found that 56% has received some didactic and 26% hands-on clinical training, and 60% had ever cared for someone with FGM/C.⁵⁰

In developing our study, we elected to use awareness of health complications related to FGM/C as our ‘knowledge’ measure. The negative health effects of FGM/C are one of the primary reasons for calls to eliminate the practice. FGM/C is considered a violation of human rights and rights of the child because it causes harm, both immediate trauma and long-term health effects.⁸⁹ Awareness of health complications is important because health care providers must be aware in order to adequately assess and treat these complications. For example, if a provider is unaware that FGM/C Type 3 is associated with recurrent UTIs, the provider may repeatedly prescribe antibiotics instead of releasing the scar as indicated.³⁰ The health care providers in our sample were on average aware of two-thirds of the complications associated with FGM/C according to the WHO index of complications. There are important limitations when considering the list of FGM/C associated complications as published by WHO. Many of the studies documenting these health complications had limited or poor-quality data characterized by small sample sizes, the lack of control groups, and analysis absent assessment for confounding factors. A recent study found that for Somali refugee women, exposure to victimization and having experienced FGM/C were each associated with increased rates of health complications.⁸⁸ Further, some of the complications associated with FGM/C are the result of iatrogenic mismanagement, rather than direct results of the health complications – such as the excess use of cesarean to avoid managing the vulvar scar from Type 3 FGM/C.⁴² Given the

recent publication of the WHO Clinical Handbook for FGM/C care, a validated measure of health care provider knowledge should be developed to strengthen future assessments. Awareness of health complications should be an important component of any future validated measure.

We developed and validated a novel measure of health care provider confidence for this study (psychometric validation presented in a separate paper). The measure includes subscales for *Confidence for Clinical FGM/C Care* and *Confidence for Critical Communications Skills for FGM/C Care*. Participants reported moderate levels of confidence for the clinical care of patients living with FGM/C with mean scores slightly lower than the median possible score. This is consistent with the findings of an existing qualitative synthesis that found health care providers are often unsure of what constitutes appropriate care for those affected by FGM/C, and many desire additional training.⁹⁰ Interestingly, having received prior training for FGM/C was not significantly associated with increased *Confidence for Clinical FGM/C Care*. This may indicate that existing trainings are inadequate, and do not provide the opportunity for health care providers to achieve some competence prior to caring for patients. Simulation based training may be an effective modality for FGM/C related care because it has been demonstrated to improve health care provider confidence and positively affect patient-outcomes, particularly for care of a relatively uncommon condition like FGM/C.⁹¹

Participants in our study reported higher levels of confidence in their communication skills with mean scores falling at the higher end of the range possible. This is a more surprising finding given existing studies with providers that note their frustration with cross cultural communication and lack of confidence with interpreter use.³² Given the research with FGM/C affected patients that demonstrates they often feel disrespected and stigmatized by their

providers,³⁷ provider confidence may be misplaced. The only factor associated with increased confidence in communication was awareness of more complications associated with FGM/C, suggesting that the first step toward increasing provider confidence is increasing their knowledge and awareness of the condition. Future research should explore how patients and providers interpret and experience communication during clinical visits to identify areas of incongruence. Research studying patient-provider communication, particularly in the presence of racial, cultural and/ or linguistic discordance, has demonstrated that health care providers often experience implicit bias that is transmitted to the patient through their communication behaviors.^{62,92} Health care providers caring for women who have experienced FGM/C in the diasporic setting may be further influenced by “othering” of African bodies, and moral superiority of opposition to FGM/C that may lead to a paternalistic and stigmatizing treatment of women living with FGM/C.²⁴

Our findings were limited in terms of factors associated with the *Negative and Empathetic Attitudes* subscales. Only one factor had a significant association – identifying as a woman was significantly associated with less negative attitudes towards FGM/C compared with identifying as a man. Women also had significantly higher scores on the *Confidence for Clinical FGM/C Care* scale. A study conducted in Spain also found significant gender differences; women were more likely to detect FGM/C cases and correctly identify FGM/C while men were more likely to include reporting women with FGM/C to the authorities as part of their response.⁵³ No other variables under investigation were significantly associated with scores on the attitudes subscales. These scales were developed for use in this study, and likely require further refinement including potentially the inclusion of additional items to broaden the range of attitudes assessed. Further, our sample was self-selected and so may have less variance in terms

of the attitudes compared with a random sample of health care providers. Finally, future research should consider investigating the association between health care provider attitudes scores and factors such as scores on a validated measure of implicit bias, and/or political affiliation which may inform attitudes toward immigrants in our current highly politicized anti-immigrant environment.⁹³

The attitudes scales that we developed were designed to be used with any health care provider, regardless of scope of practice, while the confidence scales were designed for any health care provider who provides outpatient care. Women with FGM/C require specialized consideration from all health care providers; however, there are important skills for providers who attend birth. It is concerning that only about 10% of providers who attend births have been trained to perform defibulation, an important intervention for reducing obstetric morbidity.⁸¹ Despite only 10% reporting receiving training for defibulation, about a third agreed or strongly agreed that they are confident that they could perform defibulation during the second stage of labor. This may represent an over-confidence on the part of providers. We found that almost half of providers who attend births agree or strongly agreed that a provider should perform reinfibulation if the woman requests it. This is a controversial stance given that reinfibulation is considered a form of FGM/C, and thus vehemently opposed by the WHO. This is not completely surprising given that no professional health organization has published FGM/C-specific guidelines in more than a decade. Reinfibulation is associated with similar health complications as other forms of FGM/C. However, there is a dearth of research on the consequences of *partial* defibulation and *partial* reinfibulation, which may have different outcomes related to possible physical health complications or mental health and well-being, particularly genital self-image or bodily satisfaction.²⁴ An important difference is that reinfibulation is typically performed on an

adult woman who can legally consent to the procedure. In many high-income countries in the West, medical ethicists agree that adults have the right to bodily modifications that are without direct medical benefits including cosmetic genital surgery.^{94,95} While the ethics of this debate are beyond the scope of this paper, it is important that health care providers receive adequate training regarding the ethical dilemmas they may face during the provision of care so that they are not surprised by a request, and that they may have a considerate and respectful response should a request arise.

Conclusion

Few health care providers receive any training for the care of women and girls who have experienced FGM/C, and those who have received some training are not necessarily more confident in their ability to provide appropriate clinical care for FGM/C. The overall negative attitudes toward FGMC and those affected by the practice may be consistent with overall discriminatory attitudes toward patients of color in the US. Given the gross disparities in maternal and neonatal outcomes by race, strategies to help providers recognize and mitigate their negative attitudes are imperative. The high level of willingness to perform reinfibulation paired with a lack of understanding and training on how to perform defibulation or manage a vulvar scar highlights the need for more explicit guidelines for U.S. providers. Guidelines should include a structure for providers to explore their attitudes regarding reinfibulation, obtain appropriate training for defibulation and reinfibulation, and guide providers in how to have a culturally informed discussion with patients about the health and ethical issues related to a woman's choice.

Our research has demonstrated innovative and important opportunities for the development of future education and training for health care providers caring for women and girls affected by

FGM/C. Specifically, future trainings for health care providers should include opportunities to practice clinical and communication skills through structured clinical simulations, which are more effective than didactic teaching for building health care provider confidence. Trainings should also include opportunities for discussion and reflection of individual attitudes toward the practice of FGM/C and those who are affected by the practice. Further research should explore how simulations and structured discussions around the power dynamics of providing care to marginalized and oppressed groups can further transform attitudes, confidence and quality of care.

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CHAPTER 4: MANUSCRIPT THREE

Advancing the Knowledge, Attitudes and Practices of Health Care Providers Who Care for Women and Girls Who have Undergone FGM/C: A Qualitative Exploration of Expert Opinion

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Proposed Journal: PLOS One

Date of Submission: *pending*

Abstract

Background: Female genital mutilation or cutting (FGM/C) is a cultural practice associated with numerous adverse health complications affecting more than 200 million women and girls globally and an additional 3 million are at risk each year. Women and girls living with FGM/C often do not receive high quality health care services. Qualitative research has demonstrated that health care provider attitudes are a critical nexus between knowledge and practice that may impact quality of care. The aim of this study was to explore what global clinical and research experts considered to be critical areas of knowledge and practice required for quality care, and how health provider attitudes may impact the delivery of quality care for those living with FGM/C.

Methods: We conducted 31 semi-structured individual interviews with global clinical and research experts for FGM/C from 30 countries including participants from Africa, Australia/New Zealand, Europe, the Middle East, and North America. Interview questions explored areas of knowledge, attitudes, and practices that participants believe influence quality of care for those affected by FGM/C. We used the Framework Method of qualitative data analysis to organize themes that emerged, and to explore how they interact to influence quality of care.

Results: Participants identified six areas of knowledge, six of practice, and seven of attitudes that contribute to quality care for FGM/C. Areas of knowledge include: general knowledge about FGM/C, risk factor, support for FGM/C; unaltered female genital anatomy/ physiology; health complications; management of health complications; ethical and legal considerations; and patient-provider communication. Areas of practice include: clinical procedures and protocols; management of complications; defibulation; other surgical procedures for FGM/C; pediatric care; and patient-centered care. Areas of attitudes include attitudes toward: benefits of FGM/C; harms of FGM/C; ethical issues; providing care for FGM/C-affected clients; women and girls who have experienced FGM/C; communities that practice FGM/C; and affective response to FGM/C. We present findings that describe how the interaction between knowledge, attitudes and practices influence quality of care.

Conclusions: Global clinical and research experts in FGM/C discussed comprehensive areas of knowledge, attitudes, and practices that comprise high quality care for women and girls who have experienced FGM/C. These should be integrated into future training curricula for health care providers and can be used to develop evaluation metrics. Trainings should support health care providers to increase their knowledge, and improve their clinical practice, and require that health care providers engage in self-reflection regarding their own attitudes and affective response toward FGM/C and affected patients.

Key Words (3-10 permitted): Female Genital Cutting, Female Genital Mutilation, Female Circumcision, Knowledge, Attitudes, and Practices

Background

Scope of the Problem of FGM/C

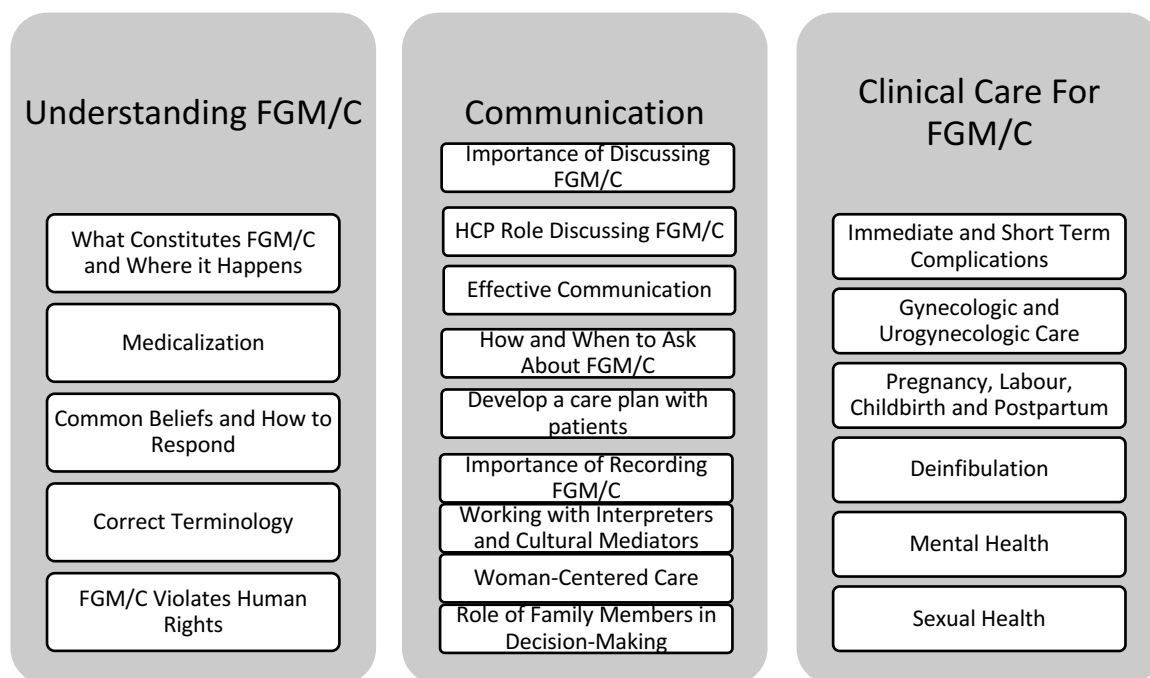
Female genital mutilation/ cutting (FGM/C) is a persistent public health problem with approximately 200 million women and girls already cut worldwide, with another 3 million at risk each year.¹ FGM/C is a cultural practice performed on girls from infancy to adolescence, depending on the setting, and involves partial or total removal of external female genitalia.¹ This practice is concentrated in 30 countries throughout the Middle East, Africa and Asia; however, due to migration, affected women and girls live around the world.¹ Although prevalence rates are falling in many countries, population growth data suggest that the total number of affected women and girls will continue to rise for several decades.² This growing population requires specialized care because FGM/C is associated with acute and chronic health complications negatively affecting genitourinary, obstetric, gynecologic, sexual, and emotional health.³ These complications are associated with a yearly estimated cost of 1.4 billion.⁴ Given the health and economic costs, there is an urgency to understand what constitutes quality care for women and girls living with FGM/C.

Care for Women and Girls Affected by FGM/C

Concurrent with the conceptualization (2016) and data collection for this study (2017-2018), the WHO published two seminal documents about this topic: the *Guidelines on the Management of Health Complications of FGM* (2016) and the *Care of Women and Girls Living with FGM: Clinical Handbook* (2018).^{5,6} The *WHO Clinical Handbook* provides a comprehensive overview of clinical care for FGM/C based on existing evidence and expert consultation, establishing a new standard for quality care for FGM/C. The WHO states that quality health care is safe, effective, timely, efficient, equitable, and person-centered.⁷ The *WHO*

Clinical Handbook addresses three broad areas: understanding FGM/C, recommended patient-provider communication strategies for FGM/C-related health concerns, and recommended clinical care strategies to manage specific types FGM/C-related health concerns that women and girls may experience (Figure 8).

Figure 8 WHO Clinical Handbook – Overview of Contents



The Clinical Care for FGM/C chapters include: identifying complications and their etiology, history taking, performing a physical exam or mental health assessment, managing complications, and referring clients for further management. In addition to the WHO publications, professional organizations in Australia, Canada and the United Kingdom have also published brief clinical guidelines that address areas such as: understanding the practice of FGM/C, ethical and legal considerations, complications associated with FGM, clinical management of FGM, child protection, communication with patients, and culturally competent care; however, emphasis and level of detail vary considerably.^{3,5,6,8–10} The WHO Clinical

Handbook represents an important advancement toward the establishment of an evidence-based guideline to establish what constitutes quality of care for women and girls living with FGM/C.

Quality of Care for Women and Girls Living with FGM/C

Despite the prevalence of FGM/C and its health burden, most health care providers have limited or no training related to FGM/C, making it difficult to provide quality care.^{11,12,21–24,13–20} Providers demonstrate knowledge deficits and lack confidence in their ability to provide quality care for clients affected by FGM/C.^{16,23,25,26} Providers report they do not know what constitutes quality care for clients living with FGM/C.^{23,27} This lack of knowledge and clinical practice expertise has two important consequences. First, providers risk failing to address the adverse effects of FGM/C, potentially causing iatrogenic injury.^{15,28} For example, a woman with Type 3 infibulation may present with recurrent genital and urinary tract infections. If the health care provider is not aware of the recommended technique of defibulation, an anterior incision to release the vulvar scar, or assume that the patient would decline defibulation, the client may not be offered this procedure that would likely improve her symptoms and quality of life.²⁹ Providers who lack knowledge about FGM/C and confidence in FGM/C-related procedures may not provide evidence based care in an effort to avoid addressing the FGM/C.³⁰ For example, a woman with Type 3 infibulation who is in labor will likely requires defibulation. If a provider is unaware of or unskilled in the practice of defibulation, they may instead perform an episiotomy or an unnecessary caesarean birth, subjecting women to unnecessary risks associated with unindicated surgical procedures.³¹ Ultimately, a provider's lack of knowledge and confidence, inappropriate practice, and imposition of their own cultural norms and values into the patient-

provider interaction may be noted by the woman and her community, and result in distrust of the health care provider and health system.³²

Health care provider attitudes toward FGM/C may further impact the quality of care by influencing the relationship between health care provider knowledge about FGM/C (including its harms and recommend treatments) and their clinical practice.³² In countries or communities where FGM/C is a normative among some ethnic groups, a provider's support or opposition to FGM/C may be informed by their knowledge of its health complications, cultural beliefs about its benefits and importance, and revenue from performing FGM/C.^{33–35} The religious importance of FGM/C in some communities may overshadow existing knowledge about its possible health complications.³⁶ Health care providers who support FGM/C may engage in *medicalization* (FGM/C practiced by any category of health care provider in clinical or non-clinical settings) as part of their clinical practice for economic benefit³³ or because they believe that FGM/C is a valuable hygienic or cosmetic procedure.³⁷ Health care providers who oppose FGM/C in communities where it is normative may face loss of income and social censure from family or community members, thus engendering a conflict between their attitudes toward FGM/C and their clinical practice.³³ Regardless of region, providers who oppose FGM/C may display shock, disgust, or pity when providing clinical care for women and girls living with FGM/C.³² Women and girls who experience these affective responses report feelings of shame, stigma, and poor body self-image.³² As a consequence, they may delay or avoid care for FGM/C.^{38,39}

Researchers seeking to assess health care providers caring for those living with FGM/C commonly use the *Knowledge, Attitudes and Practices* framework which fundamentally seek to understand the relationship between knowledge and behavior.^{40,41} The KAP framework theorizes that a subject will learn about a topic (knowledge), experience some affective response or feeling

(attitude), and then engage in a behavior (practice). The relationships between knowledge, attitudes and practice may vary considerably and are not necessarily linear. Several recent systematic reviews of studies assessing the knowledge, attitudes, and practices (KAP) of health care providers^{42,43} and their experiences providing care^{16,21}, providers are often not adequately prepared to provide quality care for those living with FGM/C. A recent systematic review of health care provider KAP surveys found considerable variability in terms of what types of items are included within existing surveys highlighting that, until recently, researchers have lacked a framework to define what constitutes quality care for women and girls living with FGM/C.⁴⁴

While the publication of the *WHO Clinical Handbook* represents an important advancement in the establishment of what constitutes quality care for women and girls living with FGM/C, it is limited in the extent to which it addresses the effect of attitudes on knowledge acquisition and clinical practice. The aim of this study was to explore the knowledge, attitudes, and practices that are important to ensuring quality care for women and girls living with FGM/C, and how these factors interact to affect quality of care. Given the concurrent publication of new comprehensive guidelines for FGM/C from the World Health Organization, we organized our findings to confirm and expand upon what is included in these publications. We further explored the ways in which health care provider attitudes may provide insights and opportunities for the further advancement of quality care for women and girls living with FGM/C. The results of this study may be used to inform the creation of health care provider trainings on this topic and to inform the construction of measures to better assess health care provider knowledge, attitudes, and practices for the care of women and girls affected by FGM/C.

Methods

Study Design

We conducted a cross-sectional qualitative study utilizing in-depth individual interviews.

Recruitment and Consent

We began recruitment by creating a purposive sampling strategy of clinical and research experts in FGM/C stratified by clinical practice area and/or research expertise, and region (high prevalence versus diaspora). We defined “high prevalence” as those countries identified by UNICEF/ WHO where FGM/C has been practiced traditionally among some communities, and ‘diaspora’ as countries where FGM/C is not normative but home to a significant number of immigrants or refugees from high prevalence countries. We created a preliminary list of potential participants in consultation with the WHO Office of Reproductive Health and Research. Inclusion criteria included clinical or research expertise in FGM/C as demonstrated by clinical practice and/or publication and research history, possession of a clinical or research degree, and the ability to conduct the interview in English or French. We contacted potential participants via email. Those willing and eligible to enroll were scheduled for an interview via their preferred modality. We sent follow-up emails to past participants requesting referrals for the strata where we had not yet enrolled enough participants.

Setting and Participants

According to participant preference, we conducted interviews in-person, via telephone, or through secure internet-based voice calls. Interviews were conducted between September 2018 and January 2019 by author CM, a nurse-midwife experienced in FGM/C care and trained in qualitative research. Interviews were conducted in English or French (via interpreter). Four

interviews were conducted in-person, and twenty-five by phone or secure HIPAA-compliant voice-over-internet-protocol (VOIP). Participants selected their own location from which to receive the interview call or conduct the in-person interview. The interviewer began by explaining the study's purpose and procedures and obtaining verbal informed consent. Interviews, which were audio-recorded with participants' permission, lasted from 45–150 minutes. Two participants provided written responses due to poor audio connection.

Qualitative Interview Guide

The semi-structured interview guide was developed by the lead author in collaboration with three other study team members with expertise in FGM/C, including a nurse-midwife, a physician specializing in obstetrics/gynecology, and a public health researcher. The guide was informed by a recent review of existing measures of knowledge, attitudes and practices.⁴⁴ The guide was written in consultation with researchers and clinicians with FGM/C expertise, and staff who focus on FGM/C from the WHO Office of Reproductive Health and Research. These collaborators provided written comments that were integrated into the interview guide. The guide explored the participant's opinion of: 1) the knowledge required to provide quality care for women and girls affected by FGM/C; 2) the clinical practices necessary for the provision of high-quality health care for women and girls affected by FGM/C; and 3) the attitudes that health care providers may hold related to FGM/C and the care of FGM/C-affected women and girls.

Analysis

Audio recordings were immediately transferred from the recording device to a secure server hosted by Johns Hopkins University and erased from the recording device. Audio

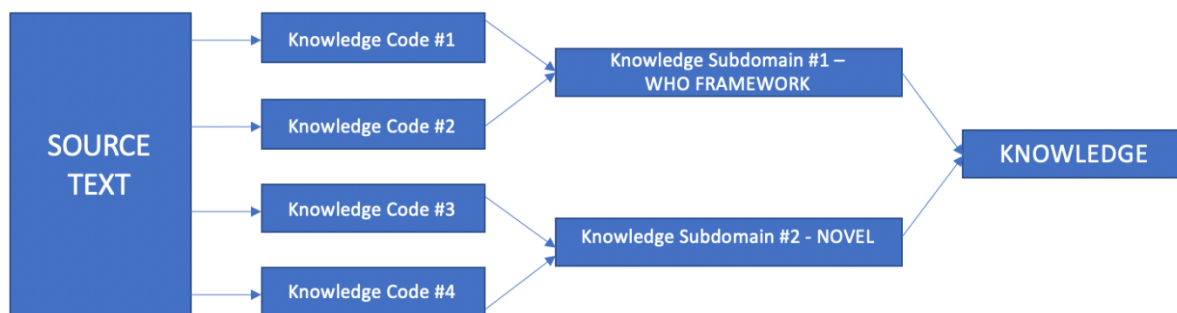
recordings were transcribed verbatim and error checked by a certified transcription and translation company. Written comments submitted in French (n=2) were translated into English for analysis.

We used NVivo 12 software for the analysis of qualitative data. We used the Framework method to integrate the qualitative data from experts with existing literature in order to confirm, revise, and expand upon what has been previously measured.⁴⁵ The Framework method analysis is an appropriate and robust method for qualitative data analysis because it enables the researcher to expand on existing knowledge and consider how existing frameworks support (or limit) the state of science. The method is particularly well-suited for data sets that cover a discrete and common set of topics, including the discrete categories of knowledge, attitudes, and practices for the care of women and girls affected by FGM. This method is useful for multi-disciplinary health research because it helps compare and contrast findings across groups (such as high prevalence and diaspora participants).

The Framework Method comprises discrete steps which we applied systematically.⁴⁵ Co-authors CM and NW led the qualitative analysis, and began by developing a preliminary codebook based on the a priori framework comprised of existing knowledge, attitudes, and practices domains published in a recent systematic review assessing the content of existing KAP measures.⁴⁴ Then, CM and NW each independently coded the same four interviews using the preliminary codebook and adding additional codes as they emerged, organizing them into the expanding codebook. CM and NW then discussed the initial independent coding, identifying differences in interpretations of existing codes, and possible additional codes. After coming to consensus on the revised codebook, NW and CM jointly wrote a brief summary of each code, capturing their main ideas to ensure consistent code application. Next, CM and NW coded the

remaining transcripts. CM and NW then compared codes again and discussed discrepancies to achieve consensus. CM and NW reviewed the source data for each code to ensure all levels of abstraction were interpretable and consistent with the included codes. CM and NW then reviewed the complete codebook and further sorted individual codes into subdomains within the knowledge, attitudes and practices domains respectively. See figure #9 for an overview of the coding process.

Figure 9 Framework Method - Process Overview



We labeled codes as being consistent with the *WHO Clinical Handbook*, as not being included in the handbook, or as having a substantially different emphasis than the ones included in the handbook. As we developed our final framework for Knowledge, Attitudes, and Practices we noted the areas that represent convergence with the WHO Clinical Handbook, general consensus within the participants interviews, and themes that diverged from both the WHO Clinical Handbook and other participants. Once we completed our framework analysis and sorting all themes into subdomains within Knowledge, Attitudes, and Practices, we then explored the codes within the attitude subdomains labelling those that addressed the intersection of attitudes with knowledge and/or practices that participants expressed may impact the quality of care. Because our aim is to create a comprehensive framework of knowledge, attitudes, and

practices to inform global guidance on FGM/C care and the development of a standardized KAP measure, we focus our presentation of results on areas there was consensus among participants.

Ethics Statement

The Institutional Review Boards of Johns Hopkins Medicine and the WHO granted research and ethical approval for the conduct of this study.

Results

We conducted a total of 31 in-depth interviews with 15 participants from high prevalence countries and 17 participants from diaspora countries. Table #19 describes the sample by region and profession.

Table 19 Qualitative Interview Participants – Region and Profession

| | Reproductive Health Providers | Primary Care/ Pediatric | Nursing | Researchers | TOTAL |
|------------------------|-------------------------------|-------------------------|----------|-------------|-----------|
| High Prevalence | 4 | 4 | 3 | 3 | 14 |
| Diaspora | 6 | 3 | 3 | 5 | 17 |
| TOTAL | 10 | 6 | 6 | 8 | 31 |

Table #20 describes the participant characteristics. The participants were mostly female (77%). Nearly half of participants held a PhD (48%), while the remainder held a clinical or Master's degree. The most common religious affiliations were Muslim (10%), None (30%) and Christian (27%). There was a wide range of ages (31-77 years old), and years conducting clinical or research work related to FGM/C (6-55 years).

*Table 20 Participant Characteristics
(n=31)*

| Characteristic | N (%) |
|-----------------------------------|--------------|
| Region of Origin | |
| - High Prevalence | 14 (45%) |
| - Diaspora | 17 (55%) |
| Highest Level of Education | |
| - PhD* | 15 (48%) |
| - MD* | 12 (39%) |
| - Masters | 3 (10%) |

| | | | |
|-----------------------------------|--------------|-------------|---------------------------|
| - DNP | 1 (3%) | | |
| Religion | | | |
| - Muslim | 10 (33%) | | |
| - Christian* | 8 (27%) | | |
| - Jewish | 2 (7%) | | |
| - None | 9 (30%) | | |
| - Decline | 1 (3%) | | |
| | Range | Mean | Standard Deviation |
| Age | 31-77 | 51.8 | 11.3 |
| Years in Profession | 5-55 | 20.8 | 10.85 |
| Years in FGMC** | 6-55 | 21.4 | 13.6 |
| *One participant reported MD/ PhD | | | |
| **3 missing values | | | |

The qualitative analysis via the Framework method resulted in six subdomains of knowledge and practices, respectively, and seven subdomains of attitudes. We have **bolded** those themes that were either not included in, or emphasis diverged significantly from, the *WHO Clinical Handbook*. See Figures #10, 11, and 12. Our analysis of the relationship between the subdomains further revealed that health care provider attitudes are constantly interacting with knowledge, and practices to inform the quality of care provided. We found that attitudes towards FGM/C, the women who have experienced it, families and communities that perpetuate the practice, and the ethical issues that arise during care can all influence a provider's knowledge and inform their clinical practices.

Figure 10 Knowledge Subdomains and Themes

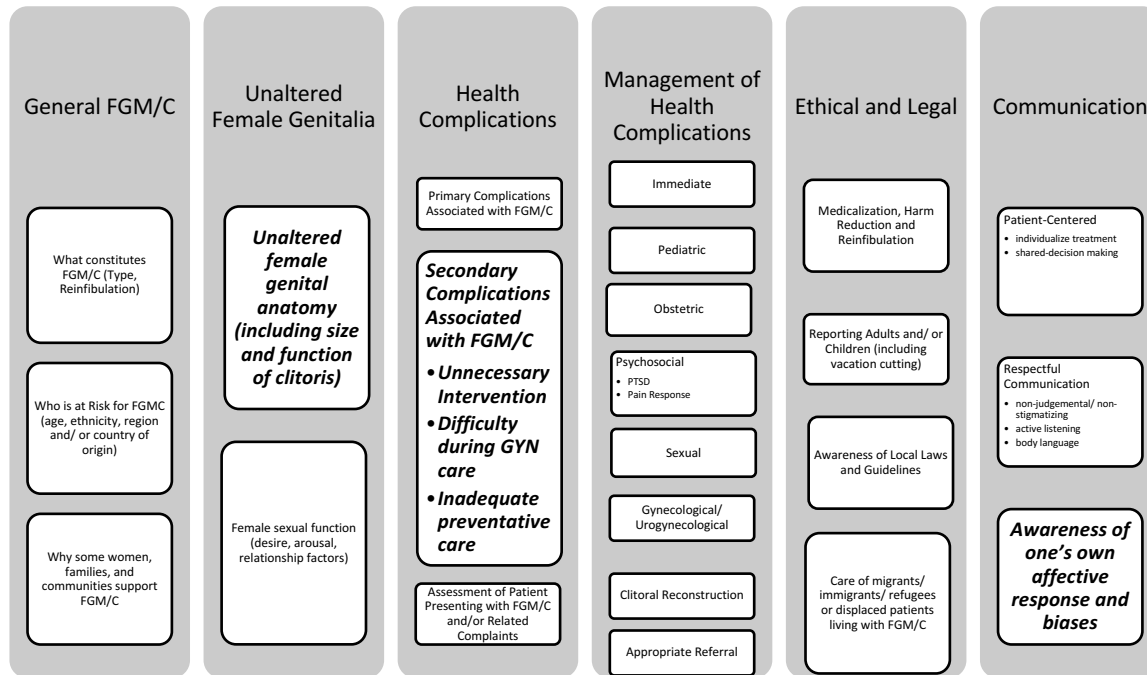


Figure 11 Attitudes Subdomains and Themes

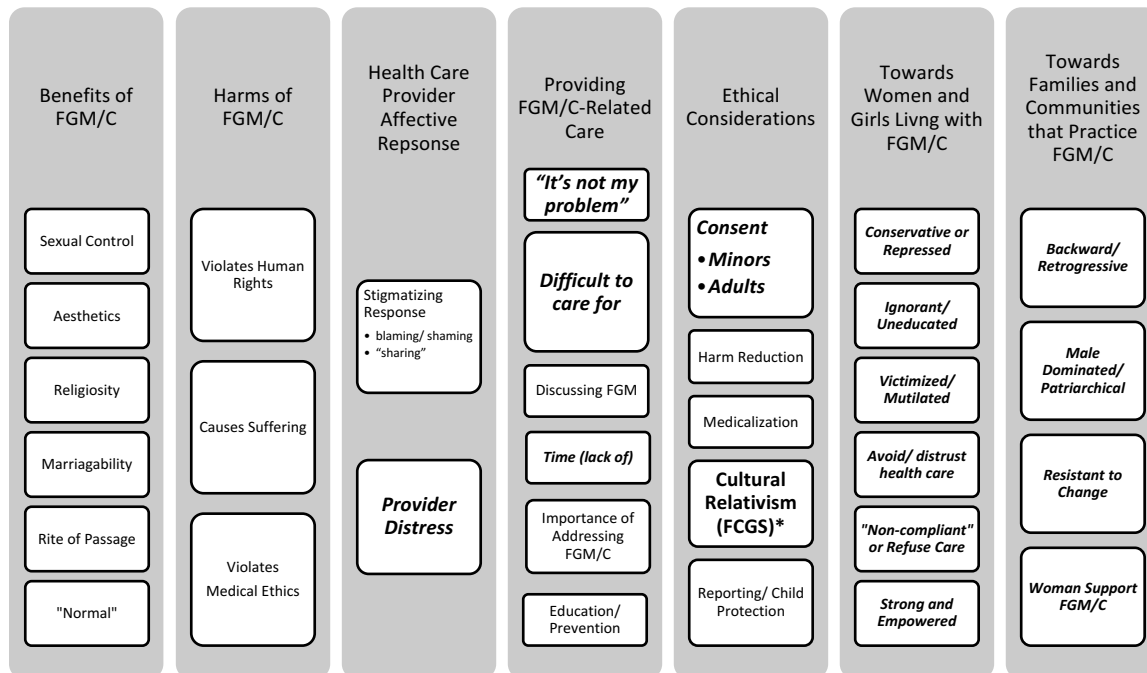
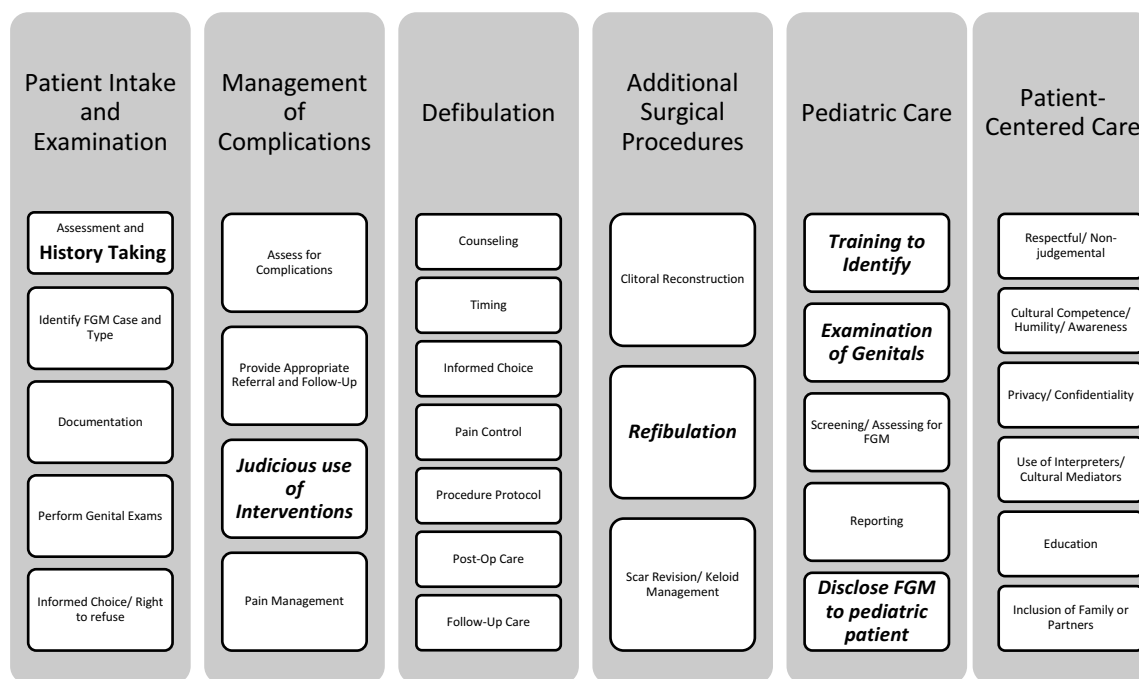


Figure 12 Practices Subdomains and Themes



Attitudes Towards FGM/C – Interactions with Knowledge and Practices

Consistent with the *WHO Clinical Handbook*, participants stated that health care providers must have a general understanding of FGM/C including being knowledgeable about the types of FGM/C (including that medicalization and reinfibulation are forms of FGM/C), who is at risk for FGM/C, and the reasons that some people support FGM/C. Beyond the *WHO Clinical Handbook*, participants stressed that it is important for health care providers to understand the social and cultural significance of FGM/C, including consequences of undergoing or not undergoing FGM/C. This knowledge informs clinical practice by influencing provider behavior for screening and assessment of FGM/C, aids the providers ability to identify FGM/C and document FGM/C cases, and refines their skill for performing appropriate genital exams for those with FGM/C. Participants reflected on the importance of asking the patient to tell her FGM/C story so that the provider can understand what the practice means to her. Consistent with the WHO guidelines, participants agreed that health care providers must understand the range of

female sexual response including the role of factors such as arousal, desire, and relationship characteristics. Participants further stressed that comprehensive knowledge about unaltered female genital anatomy and physiology is extremely important for all health care providers, including traditional birth attendants.

“ . . . some categories of midwives . . . [do] not know definitely the physiology and anatomy of these genital parts so they need to concentrate in raising their knowledge about this . . . ”
(Female, Midwife, High Prevalence/ Sudan)

This knowledge enables health care providers to identify structures affected by cutting, what symptoms a woman might experience based on what was cut, and determine what treatments might be effective to relieve symptoms.

Participants noted that health care provider attitudes regarding the benefits or harms of FGM/C, their affective responses to patients with FGM/C, and their attitude toward providing FGM/C- related care may affect quality of care particularly its effectiveness and patient-centeredness. While the benefits and harms of FGM/C discussed by participants were consistent with the *WHO Clinical Handbook*, WHO focused on how to respond to *patients* who endorse benefits of FGM/C, while participants focused on health care provider attitudes. Participants acknowledged that health care providers from communities that practice FGM/C may share beliefs about the benefits of FGM/C, disbelieve or downplay its possible harms, or believe that the benefits of FGM/C outweigh the health risks. Participants discussed how health care provider attitudes toward the benefits of FGM/C may influence how receptive they are to learning about

the harms of FGM/C, participation in medicalization of FGM/C, performance of reinfibulation, and counseling families against the practice.

A healthcare provider coming from such communities . . . [probably supports] the traditional practice because of their socialization about FGM . . . if [they don't] feel like FGM is a big thing or, an infringement of human rights, or don't feel like it has a lot of health consequences, then they might easily overlook the kinds of problems that a woman has presented. (Female, Clinical Officer, High Prevalence/ Kenya)

Participants from high prevalence countries emphasized the importance of training providers on how to respond to requests to perform FGM/C or reinfibulation, including how to manage the social or financial pressures to perform FGM/C.

Participants from both high prevalence and diaspora countries described how understanding, but not endorsing, the perceived benefits of FGM/C may cultivate compassion and empathy in a health care provider, enabling them to more effectively counsel patients about health complications without stigmatizing the woman, her family, or her community.

“ . . . [an operating room nurse from an FGM/C practicing community upon seeing a Type 3 circumcision during a cesarian birth] said ‘This is so beautiful!’ . . . that's when it really hit me that I need to honor women and really respect the value that they hold as it pertains to what's being done to their bodies that is not the Western lines of mutilation as we perceive of it.” (Female, Ob/GYN, Diaspora/ USA)

While participants uniformly agreed that FGM/C should not be performed, they cautioned that health care providers who hold strongly negative attitudes toward FGM/C risk stigmatizing and alienating their patients who find meaning and benefits in the practice.

Participants agreed that providers must be knowledgeable about the health complications associated with FGM/C and their management, referencing the *WHO Guidelines for the Management of Health Complications From FGM/C* and *WHO Clinical Handbook* as excellent resources. Consistent with the *WHO Clinical Handbook*, participants reported that midwives and Ob/ Gyns must be knowledgeable about defibulation and other surgical procedures related to FGM/C (including indications and contraindications), and be able to perform them within their scope of practice.

Attitudes Toward Providing FGM/C Care - Interactions with Knowledge and Practices

Participants highlighted that health care provider attitudes toward providing FGM/C may be a barrier to knowledge acquisition and safe clinical practice. Participants described how complications of FGM/C may be a direct result of cutting or may be due to secondary complications resulting from provider mismanagement – a nuance not highlighted in the *WHO Clinical Handbook*. Failing to address a Type 3 infibulation scar during labor and birth was frequently mentioned.

“Second might be prolonged because of soft tissue distortion. Someone might not be aware of how to manage the scar . . . they should treat early in the second stage [with defibulation] . . . if you delay, second stage might be prolonged and it's likely [the fetus is] disposed for perinatal asphyxia. (Male, Ob/ GYN, High Prevalence/ Ethiopia)

Mismanagement may be due to ignorance of evidence-based guidelines, or providers intentionally avoiding addressing FGM/C because it is unfamiliar, clinically difficult, or they are uncomfortable navigating the cultural and social implication of the plan of care.

What about patients that request reinfibulation? But [some] providers have ethical or moral reasons that they don't want to honor that. So, providers end up offering a C-section because they say, "Oh, at least we can avoid dealing with that scar." (Female, Ob/GYN, Diaspora/ USA)

WHO maintains health care providers should never perform reinfibulation; participants expressed more nuanced opinions. Participants from diaspora countries reported considerable moral distress around the opposition to reinfibulation as a cultural practice done in “other” countries compared to female cosmetic genital surgery performed in many Western countries. Some participants felt that, particularly following childbirth, that if a woman requests her vulva be repaired to approximate its appearance to match pre-childbirth/ pre-defibulation, that her wishes should be respected.

“We should not be doing reinfibulation to re-create the original infibulation. Obviously not. [But] what about those women for whom genital self-image and their sense of familiarity . . . is with their vulva covered [by FGMC]? If a woman had healthy sexual function . . . why can't we honor her request to [close the] scar above the urethra? . . . Who are we to tell them we are not going to honor her request to restore her genital

anatomy that she's comfortable with? That's a double standard when you look at Western women who can drop \$5,000 for trans-vaginal rejuvenation.” (Female, Ob/GYN, Diaspora/ USA)

Participants from both diaspora and high prevalence countries highlighted the importance of making providers aware that requests for reinfibulation may occur. Participants expressed the importance of reflecting *in advance* on how to respond to patient requests in order to support individualized care, without violating the principle of *Do no harm*. Participants encouraged health care providers to clarify their own attitudes towards the care they will offer to empower them to navigate complex discussions with patients and their families.

You have to counsel the patient about defibulation in advance [not] when the patient is in labor with her family all around. Her mother-in-law, her auntie, her grandmother, all these other matriarchal forces who may have different views on what she needs to do about her body . . . then you hear all the little clicks and heads shaking and fingers wagging from her family talking about, "No, you need to have it re-put back together” That's the reality. Women are not autonomous to make these decisions outside of the social and cultural framework of the matriarchal forces that are her social support. Being able to understand and navigate that dilemma is critical. (Female, Ob/ GYN, Diaspora/ USA)

Participants cautioned that some providers may avoid FGM/C care when they feel that it is too difficult or complex. Those health care providers may be less empathetic and more likely

to dismiss complaints associated with FGM/C. The result may be patients that are less likely to discuss their concerns, particularly when she is already struggling to overcome a taboo to discuss FGM/C.

I think FGM/C compounds that [difficulty communicating] . . . because . . . there's a taboo. You're not sure if your doctor is going to know what [FGM/C] is, whether they'll be respectful or not. There's the added dread of bringing it up, and trusting their doctors to address it in a non-judgmental way. (Female, Family Medicine, Diaspora/ USA)

The more [health care providers] show compassion the better. Even if [they] don't understand [FGM/C] and are shocked and horrified, I think managing these kinds of emotions would be important because otherwise, it's going to create more reluctance [for the patient] to say more. (Female, Anthropology, High Prevalence/ Sudan)

Participants reported that health care providers often feel that they do not have time to address all of a patient's concerns. Given limited time, providers who are less confident in their ability to address FGM/C related complaints or who believe it is not within their scope of practice, may avoid addressing FGM/C. Health care provider attitudes that result in avoiding discussion of FGM/C may contribute to other secondary complications that include delays or dismissal of routine gynecologic care and procedures. Participants described that women living with FGM/C, particularly Type 3, may not be offered routine pap smears or experience delays in obtaining procedures such as endometrial biopsy because of difficulty of introducing a speculum into their vaginas. Also, participants simultaneously emphasized that women living with FGM/C

have the right to refuse recommended care without fear of retribution and should never be forced or coerced to undergo any genital exams or procedures.

Attitudes Toward Women Living with FGM/C and Communities that Practice FGM/C

Avoidance of FGM/C care may be exacerbated if health care providers believe stereotypes of about patients who have experienced FGM/C. Negative attitudes towards patients living with FGM/C include that they are ignorant or less educated, conservative or repressed (particularly related to sex and gender norms), or lack agency as passive victims.

I think it's interesting how many people automatically seem to assume that the woman who has been circumcised is always a victim and that she lacks agency. I think that could potentially create problems. (Female, Medical Anthropology, Diaspora/ Sweden)

They should not be looked upon as criminals or those who had been subjected to harmful practice because they're not responsible for this. When they were subjected to this practice, they were unable to give their consent. They were not aware about the procedure. They were never consulted about the procedure and consider they're victims.

So, they need to be looked after. (Male, Ob/GYN, High Prevalence/ Egypt)

Participants indicated that a health care provider's belief that patients affected by FGM/C distrust health care providers, delay seeking care, or frequently refuse care can further a dynamic of mutual distrust. A health care provider's mistrust of their patient may result in mistreatment, resulting in further patient mistrust of the health system.

“ . . . if [a woman] goes and she doesn't get decent treatment, she is maltreated, she is stigmatized . . . [the doctor] starts passing unfriendly remarks . . . Of course, she will not go back again to the physician. She will not have access [to care] ” (HPRH1019)

Participants noted that it is the responsibility of the provider to *earn* the patient's trust, and should not expect it be granted based on status as a health care provider. Participants highlighted that women who have undergone FGM/C are strong and empowered and may feel quite confident in their FGM/C status. These participants stressed positive attitudes toward patients can be cultivated by health care providers, thereby promoting increased patient-centered communication and shared decision-making.

Participants described how some health care providers may have negative attitudes towards communities where FGM/C is a normative practice, and which may compromise quality of care through subtle or overt expressions of bias. Attitudes that communities that practice FGM/C are regressive or backward, or that they are strongly male-dominated/patriarchal with conservative gender norms, may lead health care providers to make assumptions about an individual patient. These assumptions can include preconceptions of how receptive she is to learning about FGM/C, what types of interventions she might consider, her plans for any girl children related to FGM/C, and the involvement from her partner or other family members. Some health care providers may believe that community commitment to FGM/C is immutable, and therefore not even worth fighting against, further leading the provider to avoid FGM/C discussions or health care. Participants stressed the importance of listening to each individual

patient and providing individualized patient-centered care based on her priorities, not preconceptions about her or her community.

Attitudes Toward Ethical Issues in FGM/C Care – Adult and Pediatric Considerations

Participants were consistently opposed to the practice of FGM/C, though their reasons varied. Some participants agreed with WHO that FGM/C is an unethical practice because it causes harm and therefore violates human rights and the medical ethical principle of *Do No Harm*. Other participants believe that it is a child's inability to legally consent to FGM/C as an elective surgical procedure is the main ethical objection rather than the possible health complications.

When you perform female genital mutilation, most of the time, you perform it on a young girl she cannot give her consent. You're violating [her] autonomy. (Male, Ob/GYN, High Prevalence/ Egypt)

For some, this leads to a stance against the genital cutting of *any* child, including male circumcision and gender assignment for those with ambiguous genitalia, because children cannot to consent to permanent bodily alterations.

I wish that all children could grow up with their genitals intact until they are old enough to give consent to any procedure. (Female, Medical Anthropology, Diaspora/ Sweden)

Following this argument, some participants felt that because adult woman are autonomous, they can consent to FGM/C. Some participants report that while they oppose the practice of FGM/C,

they feel the international opposition to the practice is problematic due to involvement of Western and White scholars from countries that permit elective cosmetic surgery, while condemning women of color who want genital alterations for cultural reasons.

“There are some women [in the West] who want cosmetic surgery on their vagina. We get questions, ‘Why can women have their labia cut for a psychological reason and not a cultural reason?’ . . . There are [minor] girls who claim that their labia are too long. They go to the doctors to cut them and they call it plastic surgery. The differentiation between that and wanting [FGM/C] for cultural issues is hard to defend because you totally ban the one operation and then you reimburse for the other. (DRH1203)

Stances against male circumcision and support of adult women’s right to elect FGM/C, including reinfibulation, conflict with WHO and other international organization positions on FGM/C. Participants stressed the importance of educators and health systems providing education and training that includes reflection and ethical case discussion so that providers can consider their response to ethical issues while continuing to provide to patient-centered care.

Participant interviews and the *WHO Clinical Handbook* were largely consistent with regards to knowledge and practices for pediatric care stressing the importance of appropriate screening and assessment and awareness of local requirements for reporting FGM/C cases. Pediatric or family provider participants highlighted the importance of receiving adequate training to perform pediatric genital examination for the identifications of FGM/C on an infant or young child because normal variation in genitals can appear to mimic Type 1 and 2 FGM/C. Providers without rigorous training might incorrectly report FGM/C. For participants in diaspora countries where parents can be convicted for subjecting a girl to FGM/C, participants discussed

the importance of awareness of mandatory reporting requirements for FGM/C cases identified during routine care, evidence of recent FGM/C, or suspected/planned vacation cutting.

Participants described the ethical challenges facing pediatric providers who fear traumatizing children by risking family separation by reporting versus protecting them from FGM/C, which may result in immediate and long-term trauma and health complications.

Pediatric providers in the diaspora discussed the importance of following a routine schedule for pediatric genital examination to ensure standard of care for *all* children and to avoid racial profiling of Black, immigrant and/or Muslim children by targeting them for genital exams. Diaspora pediatric providers highlighted the importance of communication skills when discussing FGM/C. Some immigrant adolescent girls may not have known they were circumcised.

Health Care Provider Attitudes – Effects on Communication

Consistent with the WHO Clinical Handbook, Participants stressed that health care providers must be knowledgeable about how their verbal and non-verbal communication can impact clients who are living with FGM/C, and should be skillful in their application of patient-centered communication practices. Participants further emphasized the importance of cross-cultural communication, empathy, and humility during clinical care.

“... number one is the patient-provider relationship. The ability to communicate with the patient, to build trust and have cultural humility ... knowledge or skill, that's icing on the cake! Number one, you have to be able to engage with that patient and build her trust. Empathize with her and don't belittle her. See her as a human being with dignity and respect and have that cultural humility to say, "I want to learn. Teach me. Help me understand so I

can take the best care of you, and honor or whatever is important to you, so whatever you hold and value is dear. Let me help honor that for you and how can I help you." (Female, OB/ GYN, Diaspora/ USA)

While the *WHO Clinical Handbook* does stress that health care providers should not stigmatize patients, study participants went further stating that health care providers must actively interrogate their own attitudes toward FGM/C, affected patients, and communities in order to avoid demonstrating shock, disgust, contempt, pity or other strong affective responses that may cause patients to feel stigmatized or ashamed.

"If [a health care provider] looks down upon my community and then I would say, "No, you are not the right provider to give me care." . . . If I perceive you as not caring then why would I subject myself to [you] care? You wouldn't give me appropriate care, and I would perceive that your care is not well meant" (Female, Primary Care, High Prevalence/ Kenya)

Participants stressed that health care providers must truly listen to women and avoid making assumptions about their beliefs, desires, families or communities.

"It's a recognition that you don't know it all. You need to recognize that you're here to learn and that patients are themselves are the best teachers. If we let go of our preconceived notions . . . and say, "Can you teach me? Tell me what this means to you. Help me understand so I can provide better care. What does this mean to your family, to your husband? . . . Just help build trust in order to facilitate greater patient-provider

dialogue and engagement on a very taboo and very sensitive topic.” (Female, Ob/ GYN, Diaspora/ USA)

Discussion

Clinical and research experts for FGM/C described comprehensive areas of knowledge, attitudes and practices that contribute to high quality care for women and girls affected by FGM/C. Participants expressed viewpoints broadly consistent with the *WHO Clinical Handbook* with regards to the knowledge and practices that comprise quality care for those living with FGM/C. Participants agreed that knowledge about FGM/C as a practice, female sexual function, the health complications of FGM/C and their management, ethical and legal issues that may arise, and importance of communication are critical components of quality care for FGM/C. Participants described practice areas that were consistent with the *WHO Clinical Handbook* including patient intake and examination, management of complications, use of or referral for defibulation and other surgical interventions, pediatric care considerations, and delivery of patient-centered care. While the *WHO Clinical Handbook* does not directly address the impact of provider attitudes on the delivery of quality care, it does encourage providers to *ask, listen, and reassure* their patients during clinical care. There are also “Cultural Notes” throughout to bring attention to areas for cultural awareness and sensitivity.⁶ Participants discussed seven areas of attitudes that they note may affect quality of care for FGM/C including attitudes towards: benefits of FGM/C, harms of FGM/C, appropriate affective response to patients with FGM/C, providing FGM/C care, ethical considerations, women who have undergone FGM/C, and communities the practice FGM/C.

Participants discussed additional areas of knowledge, attitudes and practices that were not included, or provided a different emphasis, in the *WHO Clinical Handbook*. Additional areas of

knowledge highlighted by participants as important for quality care include: unaltered female genital anatomy and physiology, secondary harm health care providers may cause by failing to address or mismanaging FGM/C, and the impact of provider affect and bias. Participants emphasized that providers must *practice* patient-centered communication skills, and be aware of how their own affective response (including verbal and non-verbal) may communicate stigmatizing attitudes and bias that may affect the quality of care delivered, and the patient. This theme is consistent with research that demonstrates the health care provider bias negatively affects quality of care, and can worsen patient health outcomes.^{46,47}

Participants described how health care provider knowledge is an important precursor to practice, but that provider attitudes may intervene in the pathway between *knowledge* and *practice* influencing the quality of care that is delivered. Participants described additional areas of practice that were not discussed in the *WHO Clinical Handbook*, but that were closely tied with provider attitudes. Participants discussed the importance of judicious use of interventions – that providers offer appropriate interventions to improve outcomes, but do not offer excess interventions. Participants described how health care provider discomfort with FGM/C care, belief that FGM/C care is too difficult or not their responsibility, may be more likely to over or underuse interventions. Qualitative research with providers has similarly found that when they are unsure of the best practice for care, they will tend to improvise a treatment or ignore the complaint.³⁰ For example, studies have documented that women with FGM/C, particularly Type 3 FGM/C, have higher rates of cesarean birth.^{48–50} Participants discussed that it is unclear if these excess cesareans are due to the FGM/C, which in most cases would result only in an outlet obstruction of the vulva that could be resolved quickly with defibulation, to lack of provider knowledge about defibulation, or because the provider simply wanted to avoid addressing the

scar and thus proceeded to cesarean birth. Participants reflected that even providers who are aware of defibulation may decline to perform the procedure in order to avoid discussion around reinfibulation after childbirth.

In order to ensure that patients receive high quality care, health care providers must develop awareness of their own attitudes toward FGM/C and the women and communities affected by the practice, clarify their position on ethical dilemmas that may arise during clinical practice, and remain mindful of their affective response to avoid stigmatizing the patient. It is encouraging to note that women with FGM/C who experience care where they feel valued and understood are more likely to favorably engage with preventative health services.⁵¹

The results of our study can guide the development of comprehensive training curricula for health care providers. We identified two studies that assess the effectiveness of existing health care provider trainings for FGM/C conducted in Mali and the USA respectively; however, neither used validated assessment measures or control groups, nor did they present comprehensive curriculum that could be replicated.^{52,53} Future trainings should include content from the *WHO Clinical Handbook*, and the additional areas of knowledge, attitudes, and practice that emerged from this study. Study participants discussed how health care provider attitudes may influence how they receive and integrate content of training interventions aimed to improve knowledge or transform clinical practice.

In order to effectively address knowledge, attitudes and practices, future trainings should include multiple delivery methods. Lectures and reading are effective methods for transmitting knowledge. Simulation is an effective training methodology for increasing health care provider confidence for the provision of care, particularly for care that is either higher acuity or seen irregularly in clinical practice.^{54,55} Ethical issues around FGM/C may be taught through case

studies and interactive discussions which encourage learners to engage in critical self-reflection, to articulate their own attitudes or opinions, and reflect upon how they as a provider may impact how a patient experiences the quality care she receives.⁵⁶

To our knowledge, there are no validated measures of health care provider knowledge, attitudes, and practices. Measures that do exist lack a clear framework defining each domain undermining the validity of the measures, and include inconsistent items limiting the comparability of findings.⁴⁴ The framework of knowledge, attitudes, and practices that we developed during the qualitative analysis should be used to inform the development of psychometrically validated measures to assess health care provider knowledge, attitudes and practices for FGM/C care. We plan to utilize the themes and subdomains within knowledge, attitudes, and practices that we identified during the Framework analysis to create a comprehensive item bank. This large item bank would then be pilot tested in one or more countries using rigorous psychometric methods to create a valid and reliable measure of health care provider knowledge, attitudes and practices. A future measure based on this qualitative data would allow researchers to explore the hypotheses presented by many of our study participants; namely, that health care provider attitudes affect the relationship between knowledge and practice. Researchers could then also explore how different provider, provider family, clinical setting, community or societal level factors affect health care provider knowledge, attitudes, and practices. By better understanding how health care provider attitudes affect knowledge and clinical practice, health educators and health systems continually refine trainings to address these key intersections.

Our study had many strengths and like any study, some limitations as well. Our study population includes a broad sample of clinical and research experts representing a diversity of

clinicians and researchers, disciplinary perspectives, and regions, which contributes to the trustworthiness of our study. We used a rigorous and targeted methodology for qualitative analysis and an appropriate theoretical framework to guide our study. However, we only conducted interviews with recognized experts who were available to speak or communicate via phone or internet. There may be additional expertise from clinicians and researchers working in more rural and less accessible areas that would further expand our understanding of critical knowledge, attitudes and practices. We conducted interviews only in English or French, excluding the perspective of those who do not speak those languages. By focusing on established experts in FGM/C, we may be missing the perspectives of more front-line health workers. Experts in our sample had minimal experience in Asia, so information on FGM/C in that region may be underrepresented.

Conclusion

Study participants included global researcher and clinician experts in FGM/C who described comprehensive areas of knowledge health care providers require in order to provide effective health care to women and girls affected by FGMC, attitudes that may facilitate or impede the provision of high-quality health care, and the clinical practices that comprise safe, efficient, and accessible care. The broad depth and breadth expressed in the qualitative research provides rich data from which to create comprehensive health care provider trainings, and to inform the development of a comprehensive assessments of health care provider knowledge, attitudes and practices.

ABBREVIATIONS

FGM/C – female genital mutilation/ cutting

DECLARATIONS

Ethics Approval and Consent to Participate

The Johns Hopkins School of Medicine and WHO Institutional Review Boards granted ethical approval for this study. Oral informed consent was obtained from all participants. The interviewer explained the study aim and procedures to participants, confirmed their voluntary participation, and asked permission for audio recording before beginning all interviews. Identifying information was excluded from all transcribed texts to ensure anonymity of participants.

Consent for Publication

Not applicable.

Availability of Data and Material

The data analyzed in the current study are not publicly available to protect the privacy and anonymity of the participants. Interview guides are available from the corresponding author on reasonable request.

Competing Interests

The authors declare that they have no competing interests.

Funding

This research was funded by a 2018 Heilbrunn Nurse Scholar Award, a dissertation award from the Johns Hopkins School of Nursing, and the World Health Organization. The content of this article is solely the responsibility of the authors and does not necessarily represent the official views of the WHO.

Authors' Contributions

CXM led the study conception and design, oversaw data collection and analysis, and was the primary author of the manuscript. NW assisted with data analysis, collaborated on the development of the final domain matrix, and provided critical revisions to the manuscript. CP contributed to the study conception and design, supported recruitment efforts, assisted with data analysis, and provided critical revisions to the manuscript. All authors read and approved the final manuscript.

Acknowledgements

The authors would like to thank the participants, who generously shared their expertise and opinions with us.

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CHAPTER 5: SYNTHESIS/DISCUSSION

Introduction

FGM/C is a significant public health issue that most health care providers are not adequately trained to address. This dissertation presents the first psychometrically validated measures of health care provider attitudes and confidence for the care of women and girls living with FGM/C in the US context, and findings from a qualitative exploration of global expert opinion on the knowledge, attitudes and practices that contribute to quality care for women and girls living with FGM/C globally. In order to construct the measures to assess health care provider attitudes and confidence, we conducted a comprehensive review of existing attitudes and confidence measures and guidelines for FGM/C care from global professional organizations, and utilized a conceptual approach to guide the item development. We then applied rigorous psychometric analyses to assess the reliability and validity of these novel measures of health care provider attitudes and confidence for the care of women and girls living with FGM/C in the USA. The psychometric analysis of our newly developed measures of attitudes and confidence resulted in four subscales: *Negative Attitudes toward FGM/C*, *Empathetic Attitudes toward FGM/C*, *Confidence in Clinical FGM/C Care* and *Confidence in Critical Communication Skills for FGM/C Care*. While the measures demonstrated adequate reliability, the validity testing highlighted some limitations; they may be improved with additional research. Future iterations of these subscales may include the addition of more items to increase the depth and breadth of attitudes and confidence that are assessed.

The qualitative portion of this study addressed the aim of advancing our understanding of the knowledge, attitudes, and practices that clinical and research experts for FGM/C agree are important for the provision of quality care to those living with FGM/C globally. This formative

research will inform the development of comprehensive training curricula, revisions and updates to existing guidelines establishing standard of care, and the construction of a comprehensive measure of knowledge, attitudes, and practices for use in the USA and globally.

Summary of Findings by Specific Aim

Specific Aim 1

Utilize exploratory factor analysis to assess the factor structure and psychometric properties of the newly developed attitudes and confidence scales. Further, assess the concurrent validity of the attitudes and confidence scale by testing the hypotheses that known groups would have significantly different scores on the respective scales.

We used exploratory factor analysis (EFA) for the psychometric assessment of both the attitudes and confidence scales. The exploratory factor analysis (EFA) revealed a two-factor solution for the attitudes scale, including subscales for *Negative Attitudes* and *Empathetic Attitudes* toward FGM/C and those who practice FGM/C. We assessed the reliability of the subscales using Cronbach's alpha. The *Negative Attitudes* subscale had a Cronbach's alpha of 0.814 demonstrating good reliability, while the *Empathetic Attitudes* subscale had an alpha of 0.628 which is at the lower end of acceptable reliability for a newly developed scale.

We assessed the validity of the subscales by comparing scores of known groups that we hypothesized would have significantly different scores. We hypothesized that health care providers who have ever cared for someone who had experienced FGM/C, received training for FGM/C care, or practice in a women's health specialty would have less negative and more empathetic attitudes toward FGM/C; however, there was no significant difference in scores for these groups. This may be because we used a convenience sample of health care providers who

were motivated enough to dedicate time to register for a training on FGM/C and complete an optional survey. These providers may have more similar attitudes toward FGM/C based on their interest in caring marginalized group than a random sample of health care providers. Nursing and mental health providers had significantly more empathetic and less negative attitudes toward FGM/C and those who practice compared to licensed independent providers confirming our hypothesis members of professions whose training includes the inter-personal expression of empathy as a critical skill (such as nursing and mental health) demonstrate those attitudes more strongly. Women and people of color did have significantly less negative attitudes toward FGM/C compared with men and whites, respectively confirming our hypothesis that shared lived experience of gender or as a person of color who may be more likely to have experienced bias in the health care setting as a clinician or patient who resulting in less negative attitudes.

The validity and reliability of the attitude subscales may have been further limited by a lack of variance in participant scores. Participants tended to select agree/ disagree, while selecting strongly agree or strongly disagree with the statements rarely – particularly for the empathetic attitude subscale. Further, a number of items on both subscales had >80% of participants endorsing agree/ strongly agree or disagree/ strongly disagree. The subscales may require further revision of existing items, and benefit from the inclusion of additional items that capture a wider breadth of empathetic and negative attitudes toward FGM/C and those who practice. Further, our scale would benefit from the addition of items that assess attitudes towards *providing care* to patients who have experienced FGM/C. The qualitative interviews highlighted that attitudes toward the provision of care may impact quality of care delivered, and may be unrelated to how negative or empathetic health care provider attitudes toward FGM/C and those

affected by the practice are. Future iterations of the attitude scales should include additional items, and undergo further psychometric testing in a random sample of health care providers.

The EFA for the confidence scales also revealed a two-factor solution including *Confidence in Clinical FGM/C Care* and *Confidence in Critical Communication Skills for FGM/C Care*. We assessed reliability using Cronbach's alpha, which demonstrated coefficients of 0.857 and 0.694 for the *Confidence in Clinical FGM/C Care* and *Confidence in Critical Communication Skills for FGM/C Care* subscales, respectively. The lower reliability for the *Confidence in Critical Communication Skills for FGM/C Care* may be due to a combination of factors. This subscale only includes 3-items, which can affect the Cronbach's alpha. Participants scores on these items also had limited variance with participants generally rating their communication skills highly. This again may be due to similarities within our convenience sample of health care providers who sought out additional training for the care of a marginalized population. They may have more experience in the skills assessed, such as conducting care via an interpreter, compared with a random sample of health care providers. It is also possible that while health care providers are highly confident in their communication skills, their patients may perceive the communication differently. Existing qualitative research with women who have experienced FGM/C demonstrates that many experience bias, stigma, and discrimination. Future iterations of the communication subscale should include review and consultation with women who have experienced FGM/C. Future research that compares provider self-rated confidence in communication and patient experiences of communication could further inform scale development.

Specific Aim 2

Explore the relationship between health care provider demographic characteristics, previous clinical experience related to FGM/C, awareness of health complications associated with FGM/C, attitudes towards FGM/C and those who practice FGM/C, and confidence for the care of women and girls affected by FGM/C.

Health care providers in our sample were aware of the majority of health complications associated with FGM/C; however, our sample was self-selected and may not be representative of health care providers in the US. Studies that have assessed health provider knowledge of FGM/C in the US have found that health care providers often have inadequate knowledge about FGM/C to provide quality care.¹⁻³ Though knowledge about FGM/C care tends to be low among sampled USA providers, one study of USA midwives did find that 70-90% were aware that FGM/C does result in health complications.⁴ Factors associated with increased awareness of health complications included having ever care for a woman with FGM/C or ever having received training related to FGM/C.

Health care providers in our sample tended to score toward the higher end of the *Negative Attitudes* scale indicating more negative attitudes. This finding was consistent with existing literature from women and girls with FGM/C who report that they feel health care providers often stigmatize them based on their FGM/C status.^{5,6} Scores on the *Empathetic Attitudes* scale fell were on average around the mid-range of scale, which may indicate more ambivalence around the statements that empathize with FGM/C. This finding is consistent with qualitative literature that has found health care providers experience a tension between strongly negative attitudes toward FGM/C *as a practice*, and pity or concern for the woman who has undergone FGM/C.⁷ The only statistically significant factor associated with either attitudes score was that health care providers who are women had significantly less *Negative Attitudes* toward FGM/C

compared with men. A study conducted in Spain found that health care providers who are men were more likely than women to report women with FGM/C to the authorities further indicating that health care provider gender may influence the care that is provided.⁸

Health care providers in our sample scored an average of 11.48 (possible range 5-20) on the *Confidence for Clinical FGM/C Care* scale indicating a moderate level of confidence.

Factors associated with provider's reporting higher *Confidence for Clinical FGM/C Care* include awareness of health complications, ever cared for a woman with FGM/C, being a woman, identifying as a person of color, and clinical experience of 5 or more years. Qualitative literature inform these findings by confirming that health care providers are often not confident regarding what constitutes quality care for FGM/C, and thus not confident in their ability to provide it.^{7,9,10}

A recent study in Australia found that health care providers generally lack the knowledge, training, and competency to provide sexual and reproductive health for refugee and migrant women in general, despite sexual and reproductive health being part of mainstream clinical competencies.¹¹ Given that our sample included a convenience sample of health care providers who self-selected participation, they may in fact have higher confidence for FGM/C clinical care compared to the general population of providers in the USA due to their interest in the topic of FGM/C and serving a diverse population of women.

At the time of this study, there were no USA professional organizations with published practice guidance on the care of women and girls living with FGM/C which may contribute to our findings that health care providers lack confidence for the care of FGM/C affected populations. A review conducted in 2019 found that of 47 professional organizations for health care providers in the USA, only 51% have any statement related to FGM/C and only 17 made any statement of the role of the clinician in FGM/C care. Those that did discuss clinician role

varied considerably in tone and instructional content.¹² Since publication, the American Academy of Pediatrics has published a Clinical Report for FGM/C care in girls.¹³ In 2018, around the time we began data collection for this study, the WHO published *Care of Women and Girls Living with FGM: A Clinical Handbook*, which does provide comprehensive information for clinical care.¹⁴

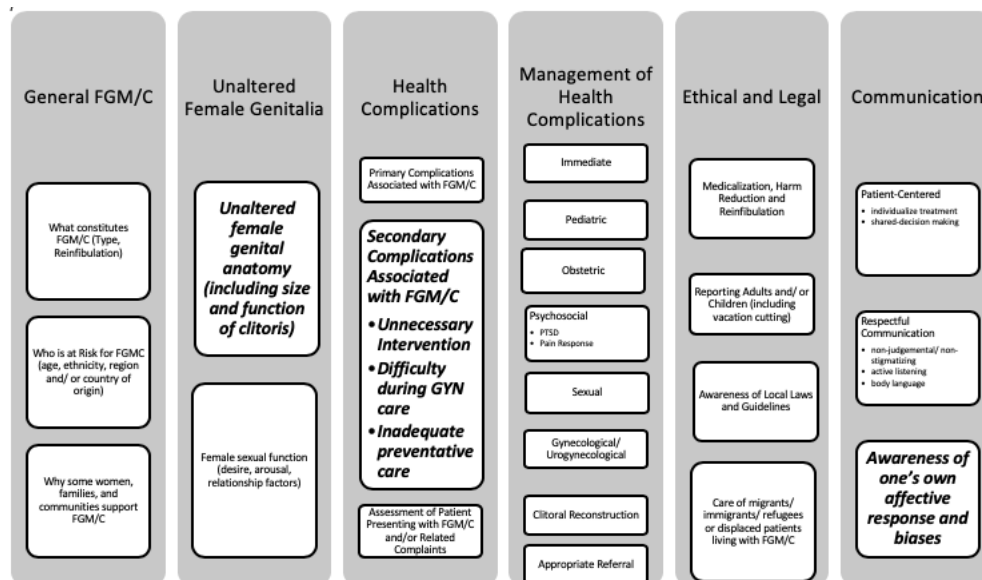
Health care providers in our sample scored an average of 9.08 (possible range 3-12) on the *Confidence in Critical Communication Skills for FGM/C Care* scale. The only factor associated with increased *Confidence in Critical Communication Skills for FGM/C Care* was awareness of health complications for FGM/C. The higher level of provider *Confidence in Critical Communication Skills for FGM/C Care* is more surprising in context of qualitative literature with patients with FGM/C who report experiencing stigma, disrespect, and bias in the clinical setting.^{6,15} Having received FGM/C training was not associated with increases in confidence for either clinical care or communication skills suggesting that existing trainings are not adequate to prepare providers to care for women and girls affected by FGM/C. Future trainings should include multiple training modalities including simulation, standardized patients, and pelvic training surgical models to ensure that health care providers have opportunities to build confidence in their clinical and communication skills, while also reflecting upon the ways their attitudes may influence care provision.

Specific Aim 3

Explore the knowledge, attitudes, and practices that global clinical and research experts in FGM/C consider important to ensure high quality, safe, and effective care for FGMC-affected women and girls using qualitative in-depth individual interviews.

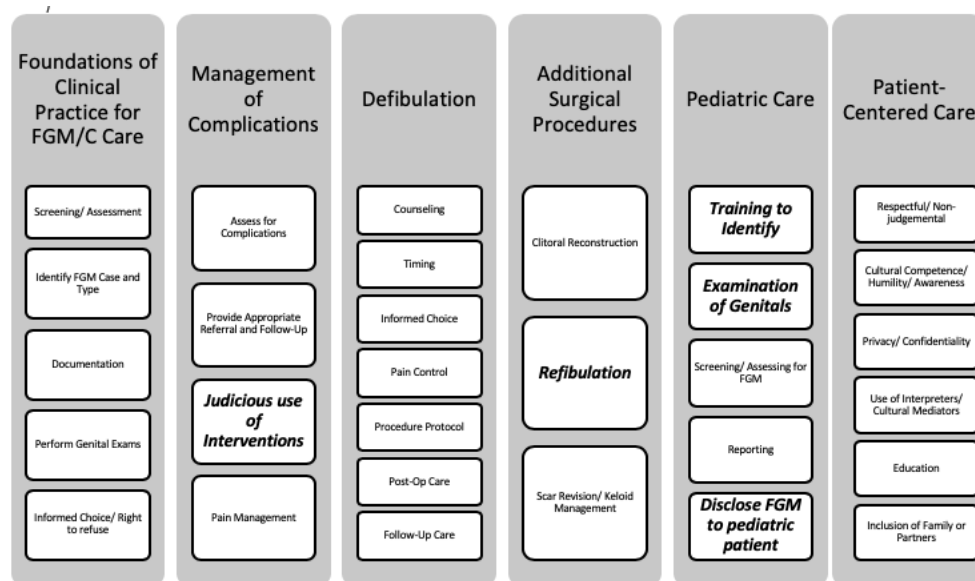
Participants identified six subdomains of knowledge that are important for the delivery of quality health care for FGM/C affected clients including general FGM/C knowledge, unaltered female genitalia, health complications, management of health complications, ethical and legal considerations, and the role of communication in quality of care. Within each subdomain of knowledge, we highlighted additional themes that emerged.

Figure 13 Knowledge Subdomains and Themes



Participants identified six domains of health care provider practice that constitute quality care to women and girls affected by FGM/C including clinical procedures and protocols, management of complications, defibulation, additional surgical procedures, pediatric care, and patient-centered care and communication. Within each subdomain of practice, we highlighted additional themes that emerged.

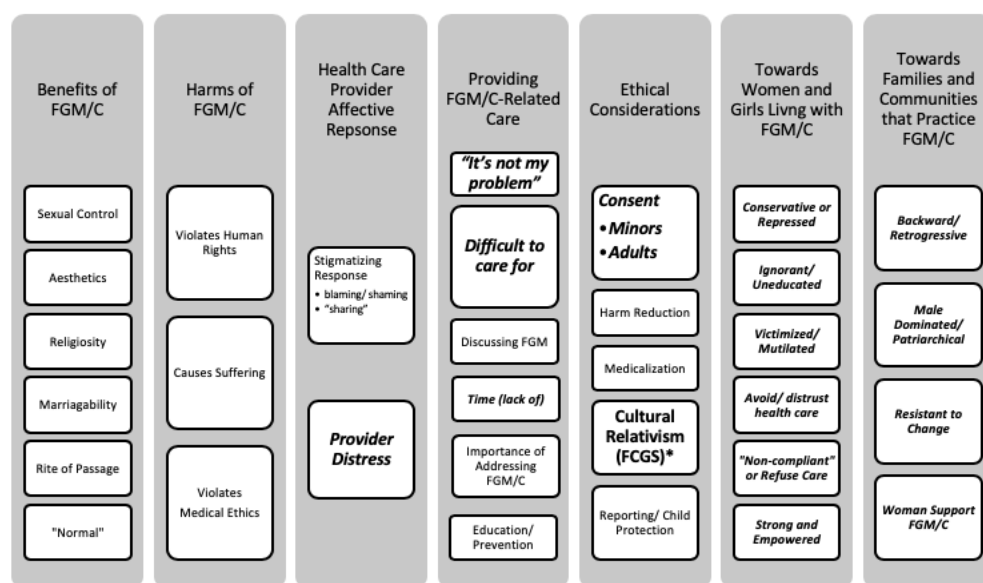
Figure 14 Practices Subdomains and Themes



Most of the subdomains and themes that emerged for knowledge and practice were also included in the *WHO Clinical Handbook*; however, there were a number of themes that emerged in the qualitative interviews that either did not appear in the *WHO Clinical Handbook*, or where the emphasis differed meaningfully noted in **bold**.

Participants identified seven areas of attitudes that health care providers must reflect on to provide quality care: attitudes towards the benefits and harms of FGM/C, attitudes toward providing care for clients affected by FGM/C and how these attitudes may influence provider affective response to a patient, attitudes toward women and girls who have experienced FGM/C and the communities that practice FGM/C, and attitudes towards various ethical issues that may arise in the course of caring for patients with FGM/C.

Figure 15 Attitudes Subdomains and Themes



Study participants expanded upon the knowledge, attitudes, and practices described in the *WHO Clinical Handbook* by including not just the biomedical processes of diagnosis and treatment, but emphasized that knowledge about the impact of one's interpersonal communication skills and practice of patient-centered communication further promote high quality care for FGM/C. A recent qualitative systematic review of healthcare experiences of women who have undergone FGM/C found that many experience cultural dissonance and feel disempowered during care due to the poor communication skills of health care providers, challenges compounded by language barriers, cultural taboos around discussing FGM/C, and health care providers who are hesitant to broach the topic.¹⁵ Future trainings and guidelines for health care provider should emphasize health care provider responsibility to gain the communication skills and confidence to address FGM/C and sexual health in a respectful and patient-centered manner. Study participants further stressed that a strong foundational knowledge of unaltered female genital anatomy and physiology should be part of training for FGM/C because many providers lack this knowledge which is critical to understanding how the cutting may impact a woman's health outcomes. The

knowledge, attitudes and practices identified by participants as contributors to quality care can be compared to findings from a recent systematic review that explored factors influencing nurses provision of sexual healthcare education: lack of knowledge, attitudes and beliefs that sexual health care is private and not a priority for the provider, discomfort addressing sexual health, and perceived barriers to providing care in the clinical setting.¹⁶

Study participants stressed that health care provider attitudes are an important contributor to quality of care. There is evidence that members of disadvantaged and marginalized groups, including immigrants, people of color, and people with low-English proficiency experience discrimination and bias during clinical care, and that these experiences result in worse health outcomes across a number of diseases and conditions.^{17,18} Attitudes may influence how receptive providers are to training interventions that aim to increase knowledge and transform clinical practice, highlighting the importance of transforming health care provider education in order to dismantle systems and attitudes that contribute to bias, racism, and discrimination.¹⁹ Attitudes may affect the quality of communication during clinical encounters in myriad ways that can promote or undermine the delivery of quality care for FGM/C affected clients therefore health care providers must receive communication skills training the aims to reduce or eliminate damaging attitudes and expressions of bias.²⁰ Health care providers must also have the insight and capacity for introspection to acknowledge that such a problem exists. Further research is urgently needed to explore how to best promote self-reflection and attitude change among health care providers.

The expanded domains of knowledge, attitudes, and practices may be use to inform future revisions of the WHO Clinical Handbook, and to inform the development of training curricula for FGM/C care. Health care providers, health educators, and health systems must

create mechanisms for reflection, discussion and transform of attitudes to promote quality of care for women and girls living with FGM/C

Discussion

Practice Implications

The findings from our survey and qualitative exploration indicated that health care provider require training to increase knowledge, transform clinical practice, increase confidence and cultivate patient-centered attitudes in order to provide quality care to women and girls who have experienced FGM/C. Nursing, midwifery, and medical educators must ensure that their curricula address the care of FGM/C affected women and girls. Training should provide didactic content to provide a comprehensive knowledge base about what constitutes effective care for FGM/C, clinical practice training to increase confidence and establish expectations for the provision of quality clinical care, and opportunities for identification, discussion, and reflection on attitudes held toward FGM/C and those who practice FGM/C. Health educators can support improved clinical practice by offering simulation based educational opportunities which has been shown to be effective in developing health care provider confidence, particularly for low frequency events such as FGM/C care in the USA, and may better influence future performance of the target practice.^{21,22} Health educators should integrate structured simulated patient encounters to support communication skills training, addressing ethical issues during clinical care, and to practice patient-centered communication. Structured simulation has been shown to be an effective strategy to improve communication, empathy and self-efficacy for nursing students.²³ Communication skills training is important to promote respectful, equitable and patient-centered care.

All health care providers, and especially those who care for marginalized and underserved groups such as immigrants and refugees, people of color and/or cultural/ ethnic minorities, and those with low-English proficiency need to be aware of the adverse effects that bias and discrimination may have on patient outcomes. In order to achieve sustained attitude transformation and behavior change, health care providers, educators and institutions must develop a culture of accountability that demands health care providers develop an awareness of their own attitudes, and promote patient-centered care for women and girls affected by FGM/C and all marginalized populations. Our research has further demonstrated that on-going training is critical as health care providers with more years of experience may express less empathy compared with newer providers. Further, it is critical that the health care workforce overall more closely reflects the populations that we serve in terms of racial, ethnic, gender, and other identities. Cultural congruence between health care providers and patients has been demonstrated to improve quality of care, markers of communication, and health outcomes for marginalized patients. Health care providers must receive comprehensive and on-going training to identify their attitudes, and mitigate or eliminate expressions of bias and discrimination in health care.^{24,25}

Policy Implications

Professional organizations for health care providers including nurses, midwives and physicians should ensure that the care of women and girls living with FGM/C are included as part of the core competencies, and that curricula are integrated into these training programs. Additional modules should be created for expanded scope of practice for health care providers who attend births including midwives, obstetricians and family medicine physicians for the management of FGM/C during labor and birth, including surgical defibulation. The American

College of Nurse-Midwives (ACNM), American Academy of Family Physicians (AAFP), American Academy of Pediatrics, and the American College of Obstetricians and Gynecologist (ACOG) have issued policy statements about FGM/C that affirm their opposition to the practice, and outline of basic competencies FGM/C care. However, these organizations should go further and develop Clinical Practice Guidelines that providers can reference for the provision of quality care. Neither the Association of Women's Health, Obstetric and Neonatal Nurses (AWOHNN) nor the American Academy of Nurses (AAN) have published any policy or guidelines related to FGM/C. These professional organizations for nurses, midwives, and physicians should not only issue policy statements regarding the practice, but also Clinical Practice Guidelines that are specific to each respective scope of practice so that health care providers can quickly access resources to ensure they provide quality care.

Recommendations for Future Research

The newly validated measures to assess health care provider attitudes and confidence represent an important advancement in the assessment of health care providers for the care of women and girls living with FGM/C. Assessing health care provider attitudes and confidence for FGM/C care is important because qualitative and quantitative literature indicate that these factors influence the quality of care women experience.^{6,26,27} Future research can explore how health care providers attitudes and confidence are related to clinical practice, and patient perceptions of quality of care, particularly patient-centeredness. These measures are the first psychometrically validated measures to assess care providers for the care of women and girls living with FGM/C. They have been developed for use in the USA, and would require further validity testing for use in other settings. The attitudes scale in particular did not have strong concurrent validity within

the sample population of US providers in Baltimore and Phoenix areas. This may be because our sample included a self-selected group of health care providers who possibly share an interest in FGM/C and immigrant/ refugee health, and thus potentially more likely to share similar attitudes. The attitudes scales should be further refined by including additional items to assess a wider range of attitudes toward FGM/C. Future research should test additional variables such as measures of implicit bias, and cultural competency as possible correlates of attitudes to further evaluate the validity of the instrument.

Our qualitative research demonstrated an expanded understanding of the knowledge and practices that constitute quality of care, and the attitudes that may affect quality of care provided to those living with FGM/C. The framework developed through the qualitative analysis including subdomains and themes within with respect domain of knowledge, attitudes, and practices should inform the development of a more comprehensive KAP measure. An important limitation of our study was the lack of patient perspectives. Further development of the KAP framework for FGM/C care should include the perspective of women and girls who have experienced FGM/C. They may have different insights related to both the areas of knowledge, attitudes and practices that are critical for quality of care for FGM/C, and understanding of how they affect their lived experience of care. The qualitative interviews would be used for formulate a comprehensive item bank that would include items with a broader depth and scope of the instrument we developed for use in the USA. Our attitudes measure included thirteen items addressing attitudes towards FGM/C, women who have experienced FGM/C, and communities that practice. A more comprehensive item bank would include all the subdomains and themes identified during the Framework analysis of the qualitative data, including attitudes toward ethical issues that may arise during FGM/C care. This future KAP instrument could be tested with a global sample of

health care providers for use in multi-country settings. This would allow for a more rigorous assessment of health care providers and inform country or region-specific training needs interventions aimed at improving quality of care for FGM/C, and patient outcomes related to FGM/C. A KAP instrument to explore relationships among health care provider characteristics, knowledge, attitudes and practices for the care of women and girls affected by FGM/C. The finding from both our US study, and the qualitative exploration of expert opinion, highlight that health care providers are not adequately trained to care for women and girls living with FGM/C. The finding from both phases of our study can inform the development of training curricula for health care providers that incorporate delivery of didactic content to increase knowledge, simulation activities to improve clinical practice and confidence, and case-based discussions to explore one's attitudes towards FGM/C and the ethical issues that may arise while providing care for those affected.

Conclusion

This research experience gave me the opportunity to explore how we assess health care providers who care for women and girls living with FGM/C. Through the collaborative research process with the team at Arizona State University, we were able to construct and assess the reliability and validity of instruments to measure health care provider attitudes and confidence. By applying rigorous psychometric methods to the assessment of these instruments, we have demonstrated both that they can be used for reliable assessment and that there is room for improvement. The qualitative study further expanded our understanding of the knowledge and practices that constitute quality care for women and girls living with FGM/C, and the ways in which attitudes may affect the quality of care that is actually delivered. Our research highlighted

the importance of training for all health care providers for the care of women and girls living with FGM/C. While the transmission of adequate knowledge about effective care for FGM/C, and the safe, accessible and efficient delivery of care are critical to the provision of quality care, they are not sufficient. Health care providers must also actively reflect on their own attitudes, engage in discussions and values clarification around ethical issues that may arise, and commit to providing care that is patient-centered and equitable. Health educators and professional organizations must ensure that all health care providers undergo trainings that encourage reflection and transformation of bias and discrimination. This might include structured evaluation during training of core competencies related to communication, and mandatory continuing education activities such as simulation, standardized patient encounters, and structured case discussions that explore stigma, discrimination and bias affecting marginalized and underserved populations. Our KAP framework and qualitative research can inform the development of a more comprehensive assessment instrument of knowledge, attitudes, and practices that may be used to evaluate the effectiveness of future trainings – further contributing the optimization of care for women and girls living with FGM/C.

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Appendices

Appendix A - Quantitative Survey

(Aim #1 and Aim #2)

INSTRUCTIONS:

The answers you provide will help us better understand the knowledge, attitudes, and practices of health care providers, and their educational needs for the care of women and girls affected by female genital cutting. The entire survey should take you approximately 15 minutes. Your answers are confidential and only aggregate or pooled results will be reported.

ELIGIBILITY:

- You provide clinical care for women and/or girls
- You are 18 years or older
- You are a licensed health care provider in current clinical practice You reside in Arizona

STUDY

ID _____

| Demographic Information – Please Circle your Response(s) | | |
|--|-----------------------------|--|
| Gender (Circle) | Race/ Ethnicity | Clinical Practice |
| Female | Black/ African American | Resident (PGY_____ Specialty_____) |
| Male | White or Caucasian | Physician (Specialty_____) |
| Transgender | Latino/ Hispanic | Nurse Midwife |
| Other | Asian American | Nurse-Practitioner (Specialty_____) |
| | Native American/ Indigenous | Physician's Assistant (Specialty_____) |
| | Other (Specify_____) | Nurse (Specialty_____) |
| | Foreign Born (Specify_____) | Social Work |
| | | Mental Health (Specify_____) |
| | | Student (Specify_____) |
| | | Other (Specify_____) |

| | | | |
|------------------------------|---|--------------------------|--|
| Religious Affiliation | Ever Cared for a Woman/ Girl with FGC? | Years in Practice | Previous FGC Training (select all that apply) |
| Muslim | | <5 | None |
| Christian | None | 5-10 | Brief Mention in a Class |
| Hindu | 1-3 | 10-20 | Full Class/Lecture During Training |
| Jewish | 3-20 | >20 | CME/CNE/ CEU Course |
| Buddhist | >20 | | Independent learning (read articles) |
| Other (Specify_____) | | | Trained with FGC-Specialist |
| | | | Other (Specify_____) |

I am affiliated with the following health care facility: _____

| Knowledge and Experience with FGC – Please Circle Your Response(s) | |
|--|---|
| Are you aware of the WHO Classification System for FGC? | Some circumcised women in the United States avoid health care for pregnancy and/or gyn conditions because they feel (select all that apply): |
| YES | 1. Stigma from Providers |
| NO | 2. Providers do not know how to care for them due to FGC |
| | 3. Legal Concern |
| | 4. Fear of Unnecessary Procedures |
| | 5. Fear of Death |
| | 6. They do not avoid care |
| | 7. Unsure |

| | | |
|--|---|--|
| It is illegal to transport a person outside the United States for FGC (vacation cutting)? | FGC performed on a child is considered assault, and therefore reportable as child abuse. | I am familiar with laws in my state regarding FGC |
| TRUE | TRUE | TRUE |
| FALSE | FALSE | FALSE |

| | | |
|---|--|--|
| Defibulation, re-opening the vulvar scar, can be an important intervention to reduce obstetric risk for women with Type 3 FGC (infibulation). 1. Have you heard of defibulation before today? YES NO 2. Were you trained on the surgical technique of defibulation? YES NO | | |
| INSTRUCTIONS: • The following table includes potential FGC-related complications that women/girls may experience. • Please Mark X if you were AWARE of the possible complication before today, if not leave blank. | | |

| | | | |
|---|-------------------------------|--|--|
| <ul style="list-style-type: none"> Please Mark X if you have SEEN the complication in your clinical practice, if not leave blank | | | |
| IMMEDIATE POST-FGC COMPLICATIONS | | | |
| | Aware of Complication? | Seen Complication in My Practice? | If yes you have seen, in which country? |
| Hemorrhage | | | |
| Pain | | | |
| Hemorrhagic, neurogenic or septic shock | | | |
| Genital tissue swelling | | | |
| Genital and reproductive tract infections | | | |
| Urinary tract infections | | | |
| Acute urinary retention | | | |
| Dysuria | | | |
| Damage to urethra and adjacent tissues | | | |
| Death | | | |
| FGC-RELATED | | | |
| OBSTETRIC COMPLICATIONS | | | |
| | Aware of Complication? | Seen Complication in My Practice? | If yes you have seen, in which country? |
| Cesarean section | | | |
| Postpartum hemorrhage | | | |
| Episiotomy | | | |
| Prolonged labor | | | |
| Obstetrical tears/lacerations | | | |
| Instrumental delivery | | | |
| Labor dystocia | | | |
| Extended maternal hospital stay | | | |
| Stillbirth or early neonatal death | | | |
| Infant resuscitation at delivery | | | |
| FGC- RELATED SEXUAL COMPLICATIONS | | | |
| | Aware of Complication? | Seen Complication in My Practice? | If yes you have seen, in which country? |
| Decreased lubrication during sexual intercourse | | | |
| Reduced frequency of orgasm or anorgasmia | | | |
| Dyspareunia (pain with sex) | | | |
| Decreased sexual satisfaction | | | |
| Reduced sexual desire and arousal | | | |
| FGC- RELATED PSYCHOLOGICAL COMPLICATIONS | | | |
| | Aware of Complication? | Seen Complication in My Practice? | If yes you have seen, in which country? |
| PTSD | | | |
| Anxiety | | | |
| Depression | | | |

| FGC-RELATED LONG-TERM COMPLICATIONS | | | |
|-------------------------------------|------------------------|-----------------------------------|---|
| | Aware of Complication? | Seen Complication in My Practice? | If yes you have seen, in which country? |
| Chronic vulvar and clitoral pain | | | |
| Recurrent genital tract infections | | | |
| Dysmenorrhea | | | |
| Recurrent UTIs | | | |
| Urinary obstruction | | | |

INSTRUCTIONS:

- The following statements reflect different attitudes toward the practice of Female Genital Cutting, and the people who practice Female Genital Cutting.
- Read each statement carefully, and MARK X in the box to indicate whether you *Strongly Agree, Agree, Disagree, or Strongly Disagree*.

| ATTITUDES TOWARDS THE PRACTICE OF FGC | | | | |
|--|----------------|-------|----------|-------------------|
| | Strongly Agree | Agree | Disagree | Strongly Disagree |
| FGC is a violation of human rights | | | | |
| Symbolic nicking or cutting of the female genitalia is an effective way to reduce the harm of FGC compared to more extensive procedures | | | | |
| Health Care Providers who perform any form of FGC, including symbolic nicking, should be charged with a crime | | | | |
| Adult women have the right to undergo FGC | | | | |
| Parents have the right to have their daughters circumcised (undergo FGC) | | | | |
| Cultural humility (the ability to maintain an interpersonal stance that is other-oriented (or open to the other) in relation to aspects of cultural identity that are most important to the [patient]) | | | | |
| of the health care provider is an important factor in reducing adverse outcomes for FGC-affected women and girls | | | | |
| Health care providers should perform reinfibulation (re-closing of the vulvar scar following childbirth) if the woman requests it | | | | |

| ATTITUDES TOWARD THOSE WHO PRACTICE FGC | | | | |
|--|----------------|-------|----------|-------------------|
| | Strongly Agree | Agree | Disagree | Strongly Disagree |
| Communities that practice FGC are oppressive towards women | | | | |
| Communities that practice FGC are honoring an important cultural tradition | | | | |
| Parents who have their daughter circumcised are abusing them | | | | |
| Parents who have their daughter circumcised are protecting her future marriage prospects | | | | |
| Women who have undergone FGC are empowered agents | | | | |
| Women who have undergone FGC are victims of an oppressive cultural practice | | | | |

INSTRUCTIONS:

- The following statements ask you to reflect on how CONFIDENT you feel in regards to different skills needed to care for women and girls affected by FGC.

| <ul style="list-style-type: none"> Read each statement carefully, and MARK X in the box to indicate whether you <i>Strongly Agree</i>, <i>Agree</i>, <i>Disagree</i>, or <i>Strongly Disagree</i> with the statement. | | | | |
|--|----------------|-------|----------|-------------------|
| Health Care Providence Confidence Caring for Women and Girls Affected by FGC | | | | |
| | Strongly Agree | Agree | Disagree | Strongly Disagree |
| On inspection of the female genitalia, I can identify a woman with FGC | | | | |
| On identification of a woman with FGC, I can assign the appropriate WHO Type classification | | | | |
| On identification of a woman with FGC, I can appropriately code a visit to document the presence and type of FGC using ICD-10 and CPT codes | | | | |
| Conduct an effective reproductive/sexual health history via an interpreter | | | | |
| Respond to the health concerns of women with FGC by engaging in non-judgmental listening | | | | |
| Counsel women on the possible complications she may experience related to FGC | | | | |
| Discuss defibulation with pregnant women who have undergone Type 3 FGC in a culturally sensitive manner | | | | |
| Perform defibulation of an FGC-related vulvar scar | | | | |
| Perform defibulation during the second stage of labor | | | | |
| Respond to a request for reinfibulation (re-closing of the vulvar scar following childbirth) with cultural humility | | | | |
| Create a positive therapeutic relationship with a patient who is refuses a recommended procedure | | | | |

Appendix B - Qualitative Interview Guide

(Aim #3)

Knowledge

- I. Please tell me about your past experiences learning about FGM.
 - a. *Probe:* Did you receive any training?
 - b. *Probe:* Was your training adequate?
- II. I'd like to learn more about what you think are the most important things that health care providers should know when caring for women with FGM?
 - a. *Probe:* What are specific care-related issues related to FGM type?
 - b. *Probe:* Are there particular biomedical or physiological aspects of care that a health care provider caring for an FGM-Affected woman or girl should know?
 - c. *Probe:* Are there particular psychological aspects of care that a health care provider caring for an FGM-Affected woman or girl should know?
 - d. *Probe:* Are there particular social or community related factors that a health care provider caring for an FGM-Affected woman or girl should know?
- III. What do you think health care providers need to know about sexual function for women with FGM?
- IV. What are some barriers that women face in getting care for problems associated with FGM?
 - a. *Clarification:* Barriers might include structural barriers (cost, health care system), or individual (lack of knowledge that care is available, normalization of adverse effects, a family member limiting access to care).
 - b. *Probe:* Are there ways you think that health care providers could help minimize or lessen some of these barriers?
- V. What are some ethical considerations related to FGM-related care for women and girls that health care providers should address?
- VI. Is there anything else you would like to add about health care provider knowledge caring for women and girls by FGM?

Practices

- I. What kinds of clinical practices do you think researchers (WHO?) should measure when they study health care providers caring for women and girls affected by FGM?
- II. What are some clinical practices by health care providers in the care of women with FGM that could improve health outcomes for FGM-affected women and girls?
- III. What are some clinical practices by health care providers in the care of women with FGM that may be worsening health outcomes for FGM-affected women and girls?
- IV. For women considering defibulation, what steps should a health care provider take before, during and after the procedure?
- V. Are there other surgical procedures health care providers should be aware of in order to care for women and girls affected by FGM?
 - a. *Probe:* Can you describe more about what should happen before, during, and after this procedure?
 - b. *Probe:* Are you familiar with clitoral reconstruction? (If yes . . .) Can you describe more about what should happen before, during, and after this procedure?

Now I have some questions about how a health care provider might respond when faced a patient request related to FGM:

- VI. What do you do or say when a woman requests reinfibulation?
- VII. What do you do/say when a family asks you to perform FGM on her daughter? (type I/II/III/IV)
- VIII. How might a health care provider contribute to the prevention of FGM?
- IX. Is there anything else you would like to add about health care provider practices caring for women and girls by FGM?

Attitudes

- I. Tell me about your past experiences taking care of women who have FGM?
 - a. For example, tell me about how you relate to them in the clinical setting?
 - b. Have you had any positive experiences? Tell me more
 - c. Have you had any negative experiences? Tell me more
- II. Tell me about what you think about the practice of FGM?
 - a. Probe: Do you think FGM causes any harm?
 - b. Probe: Do you think FGM has any benefits?
- III. How have your past experiences with FGM affected how you think or feel about the practices?
 - a. Probe: How has your training around FGM affected your feelings toward FGM as a practice?
 - b. Probe: How has your training around FGM affected your feelings toward the women and girls affected by FGM?
 - c. Probe: How has your training around FGM affected your feelings toward the communities that continue to practice FGM?
- IV. How might a health care provider's feelings toward FGM affect the patient?
 - a. Probe: What about the patient's relationship with their provider?
 - b. Probe: What about a patient's health seeking behavior?
 - c. Probe: What about the patient's choice of a treatment?
- V. Why do you think some health care providers perform FGM?
 - a. Clarification: When health care providers perform FGM it is often referred to as "medicalization."
- VI. Is there some experience that you have had that most strongly influences your beliefs or feelings toward FGM?
 - a. Probe: What do you think is the role of a hospital or department of health in regulating the practice of FGM?
 - b. Probe: What do you think is the role of a hospital or department of health in regulating the care of women and girls affected by FGM?
 - c. Probe: Can you tell me if some policy at your hospital/ department of health/ institution has influenced or changed your attitudes towards FGM?

Now I have some questions about the role of family and culture for women and girls affected by FGM:

- VII. What do you think is the role of the patient's partner? Family? In-laws in decision making about FGM?
 - a. Probe: What are some considerations for married vs. unmarried adult women?
 - b. Probe: What are some considerations around care of the pediatric patient affected

- by FGM? What is the role of the parents?
- VIII. What do you think of women who have been cut? And of those who are not cut?
 - IX. How might a health care provider's attitudes toward communities/ religions/ ethnicities/ nationalities that practice FGM affect the patient?
 - X. What social norms and values might influence a health care provider's attitudes towards the practice of FGM?
 - a. *Probe:* Towards women and girls affected by FGM
 - b. *Probe:* Towards communities that practice FGM
 - c. *Probe:* Towards the clinical care of women with FGM
 - XI. Can you tell me about any community or social norms that have particularly influenced your attitudes toward FGM

CURRICULUM VITAE

PERSONAL DATA

Christina P. Marea, M.A., MSN, RN, CNM, PhD (c)

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Johns Hopkins University

525 N. Wolfe St.

Baltimore, MD 21205

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1031 5th St NE

Washington DC 20002

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EDUCATION

| Years | Degree/Coursework | Institution |
|--------------------|---|---|
| Aug 2013 – Present | PhD Candidate | Johns Hopkins School of Nursing Baltimore, MD |
| May 2010 | Master of Science in Nursing | Yale School of Nursing New Haven, CT |
| May 2008 | Master of Arts in Conflict Resolution | University of Bradford, Bradford, West Yorkshire, UK |
| May 2002 | Bachelor of Science in Foreign Service | Georgetown University Washington, DC |

Fellowship: Better Selves Fellowship, Knoll Farm, Vermont, USA, 2017
University of Bradford, Rotary World Peace Fellowship, West Yorkshire,
United Kingdom, 2006-2008

CURRENT LICENSE AND CERTIFICATION

| Years | Source | Type |
|--------------|---|--|
| 2010 – 2022 | District of Columbia, Board of Nursing | Certified Nurse Midwife Advanced Practice Registered Nurse License No: RN1020288 |
| 2010 – 2022 | American Midwifery Certification Board | Certified Nurse Midwife |

PROFESSIONAL EXPERIENCE

| Years | Position | Institution/Location |
|----------------|---|---|
| 2013 - Present | Instructor, Nurse-Midwifery/ WHNP | Georgetown University School of Nursing and Health Sciences, Washington DC |
| 207 – 2019 | External Consultant | World Health Organization, Geneva, Switzerland (remote) |
| 2013 - 2019 | Coordinator for Simulation, Nurse-Midwifery/WHNP | Georgetown University School of Nursing and Health Sciences, Washington DC |
| 2018 - Present | Per Diem Certified Nurse Midwife | Community of Hope Washington, DC |
| 2015 – 2017 | Certified Nurse Midwife | Providence Hospital Washington DC |
| 2014 – 2015 | Certified Nurse Midwife | Physicians and Midwives Alexandria, VA |
| 2012 – 2013 | Certified Nurse Midwife | Doctors Without Borders, Maban, South Sudan |
| 2010 - 2012 | Faculty Certified Nurse Midwife | Medstar Washington Hospital Center, Washington DC |
| 2009 – 2010 | Registered Nurse | Fair Haven Community Health Center, New Haven, CT |
| 2009 | Co-Director | Haven Free Clinic, New Haven, CT |
| 2008 | External Consultant | UNHCR/ UNRWA, Damascus, Syria |
| 2007 | Certified Professional Midwife | Hospitalito Atitlan, Santiago Atitlan, Guatemala |
| 2006 – 2007 | Certified Professional Midwife | Maternidad La Luz, El Paso, TX |
| 2003 – 2004 | Marketing Associate | Advisory Board Company, Washington DC |
| 2002 – 2005 | Director | Learning Enterprises, Washington DC |

HONORS AND AWARDS

| Years | Honors/Awards | Institution/Location |
|--------------|---|--|
| 2018 – 2020 | Heilbrunn Nurse Scholar Award | Heilbrunn Foundation, Rockefeller University |
| 2017 | Fellow | Better Selves Fellowship |
| 2017 | Professional Development Award | Johns Hopkins University, School of Nursing |
| 2015 – 2016 | TL1 Trainee Award, Predoctoral Clinical Research Training Program | Johns Hopkins Institute for Clinical and Translational Research |
| 2013 – 2015 | T32 Predoctoral Training Grant for Study of Violence, Fellow, | Jacquelyn Campbell, PI, NINR, NIH, T32 HDO64428, Johns Hopkins |

| | | |
|------|---------------------------------------|--|
| 2017 | Rotary World Peace Fellow | University School of Nursing Rotary Foundation, University of Bradford, West Yorkshire, UK |
| 2018 | Sigma Theta Tau – Delta Mu Chapter | Yale University |

RESEARCH

| Years | Research Activities | Project |
|--------------------------------|--|--|
| January 2017 – January 2020 | Literature review. Manuscript development, Study Protocol Design and Management, Survey Design and Psychometrics | Optimizing Care for Women and Girls Affected by FGM/C, Office of Women’s Health/ Department of Health and Human Services |
| June 2017 – May 2019 | Study Protocol Design, Literature Review, Qualitative Interviews and Coding, Manuscript Development | Construction and Validation of a Knowledge, Attitudes, and Practices Instrument for Health Care Providers Caring for FGMC-Affected Populations |
| May 2017 – May 2018 | Survey review and development, research partner relationship management, manuscript development | Impact of Culturally-Specific Danger Assessment on Safety, Mental Health and Empowerment |
| January 2014 – June 2018 | Study Protocol Design, Literature Review, Qualitative Interviews and Coding, Manuscript Development | Gender-Based Violence on Ethiopian University Campuses |
| June – July 2015 | Qualitative interviews, study team collaboration | Communities Care |

Sponsored Projects

Agency: World Health Organization
Identifying Number: ERC.0003031
Title of Project: Construction and Validation of a Knowledge, Attitudes, and Practices
Instrument for Health Care Providers Caring for FGMC-Affected Populations
Dates of Project Period: August 2017 – May 2020
Corresponding PI: Christina Marea
Total Direct Costs over all years of award: \$50,000
Total Indirect Costs over all years of award: \$ NA
Total Direct plus Indirect Costs over all years of award: \$ NA
Role on Project: Co-Principal Investigator

PRACTICE - NA

SCHOLARSHIP

i. Peer-Reviewed

1. *In Press*: Njie-Carr, V.P.S., Sabri, B., Messing, J.T., Ward-Lasher, A., Marea, C., Wachter, K., & Campbell, J. (2020). Understanding intimate partner violence among immigrant and refugee women: A grounded theory analysis. *Journal of Aggression, Maltreatment, & Trauma (JAMT)*. <https://doi.org/10.1080/10926771.2020.1796870>
2. Kaufman, M. R., Grilo, G., Williams, A., **Marea, C. X.**, Fentaye, F. W., Abebe Gebretsadik, L., & Yedenekal, S. A. (2019). The Intersection of Gender-Based Violence and Risky Sexual Behaviour among University Students in Ethiopia: A Qualitative Study. *Psychology & Sexuality*, null-null. <https://doi.org/10.1080/19419899.2019.1667418>
3. Kaufman, M. R., Williams, A. M., Grilo, G., **Marea, C. X.**, Fentaye, F. W., Gebretsadik, L. A., & Yedenekal, S. A. (2019). “We are responsible for the violence, and prevention is up to us”: a qualitative study of perceived risk factors for gender-based violence among Ethiopian university students. *BMC Women’s Health*, 19(1), 131. <https://doi.org/10.1186/s12905-019-0824-0>
4. Nersesian, P. V., Starbird, L. E., Wilson, D. M., **Marea, C. X.**, Uveges, M. K., Choi, S. S. W., ... Cajita, M. I. (2019). Mentoring in research-focused doctoral nursing programs and student perceptions of career readiness in the United States. *Journal of Professional Nursing*, 35(5), 358–364. <https://doi.org/10.1016/J.PROFNURS.2019.04.005>
5. Alvarez CP, Davidson PM, Fleming C, Glass NE. Elements of effective interventions for addressing intimate partner violence in Latina women: A systematic review. *PLoS One*. 2016;11(8):1-13. doi:10.1371/journal.pone.0160518
6. Grace KT, Fleming C. A Systematic Review of Reproductive Coercion in International Settings. *World Med Heal Policy*. 2016;8(4):382-408. doi:doi:10.1002/wmh3.209

Conference Meetings/ Presentations

International

1. **Marea C**, Evans M, Warren N, Pallitto C. Knowledge, Attitudes and Practices of Health Care Providers for Female Genital Cutting: A Qualitative Exploration. 3rd International Expert Meeting on Female Genital Mutilation / Cutting Sharing data and experiences, improving collaboration. 2019 May 20-22. Brussels, Belgium
2. **Marea C**, Johnson-Agbakwu C, Fox K. Female Genital Cutting (FGC) Status of Daughters and Family Decision-Making Among Somali Refugee Families in Arizona: A Mixed Methods Analysis. XXII FIGO Congress. 2018 October 14-19. Rio de Janeiro, Brazil
3. Njie-Carr V, Sabri B, Messing JT, Suarez C, Ward-Lasher A, **Fleming C**, Campbell J. Engendering Resilience to Survive in the Lives of Abused Immigrant and Refugee Women: A Grounded Theory Study. Nursing Network on Violence Against Women International. 2018 September 27-29. Niagara-On-The-Lake, Ontario, Canada.

4. Njie-Carr V, Sabri B, Messing JT, Suarez C, Ward-Lasher A, **Fleming C**, Campbell J. Common and Culturally Specific Factors Related to Intimate-Partner Violence among Immigrant and Refugee Women: Implications for Safety Planning. Nursing Network on Violence Against Women International. 2018 September 27-29. Niagara-On-The-Lake, Ontario, Canada.
5. **Fleming C**, Evans M, Warren N, Johnson-Agbakwu C. Development and Evaluation of an Evidence-Based Training Workshop for Health Care Providers Caring for Women and Girls Affected by Female Genital Cutting (FGC). 12th Biennial Conference of the Global Network of WHO Collaborating Centres for Nursing and Midwifery. 2018 July 18-19. Cairns, Australia.
6. **Fleming C**, Evans M, Warren N, Johnson-Agbakwu C. Health Care Provider Competencies Caring for FGC-Affected Populations – A Conceptual Map. 2nd International Expert Meeting on Female Genital Mutilation / Cutting Sharing data and experiences, improving collaboration. 2018 May 28-29. CHU Sainte-Justine, Montreal, Canada.

National

7. Nersesian P, Starbird L, Choi S, Wilson D, **Fleming C**, Kurtz M, Szanton S. Mentoring in research doctorate nursing programs and students' perceived career readiness. Nursing Education Research Conference. 2018 April 2019-2021. Washington, D.C., USA.
8. Worly B, Heinrichs G, **Fleming C**. Sexual Health Education – How to Handle the Hard Stuff. Association of Professors of Gynecology and Obstetrics Conference. 2018 January 6-9. Palm Beach, Florida, USA.

Local

1. Invited Speaker, Racism and Maternal Health Disparities, Howard University, Washington, DC, March 2019
2. Podium Presentation, Global Midwifery, Johns Hopkins University School of Nursing Midwifery Week, Baltimore, Maryland, October 2016
3. Invited Speaker, Humanitarian Aid – Working with Doctors Without Borders, Johns Hopkins University School of Nursing, Baltimore, Maryland, 2013
4. Invited Speaker, Johns Hopkins University School of Advanced International Studies, Global Women in Leadership Celebrating International Women's Day, March 2016

EDITORIAL ACTIVITIES – NA

PROFESSIONAL ACTIVITIES

Co-Chair, DC Maternal Mortality Review Commission

June 2019 – Present

Sigma Theta Tau International

2018 – present, Member

American College of Nurse Midwives

2020 – Present, Racism and Midwifery Education Task Force

2010 – Present, Member

2007 – 2010, Member, Students and New Midwives Section

American College of Nurse Midwives, District of Columbia Affiliate

2010 – present, Member

PROFESSIONAL SOCIETY MEMBERSHIP

Dates (in Years) of Membership Society Name, Leadership Role (if appropriate)

1. 2010 – Present; ACNM Chapter, Washington, DC
2. 2018 – Present; Sigma Theta Tau International Nursing Honor Society, Nu Beta Chapter
3. 2016 – Present; National League of Nursing

EDUCATIONAL ACTIVITIES

Georgetown University, Midwifery/ Women's Health Nurse Practitioner

Courses Taught: Primary Care of Women, Evidence Based Practice Research 2, Health Care Ethics, Families in Crisis, Integrated Midwifery Care of Women, Full Scope Midwifery Care II, Advanced Women's Healthcare Seminar, Introduction to Women's Reproductive Health

Johns Hopkins University, School of Nursing

Courses Taught: Global Health Nursing

ACADEMIC SERVICE

Nursing Structure 2020 Task Force

Georgetown University, School of Nursing and Health Studies